



THE IMPACT OF INFORMAL CAREGIVING IN STROKE: burden, positive gains and quality of life

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29th September, 2021

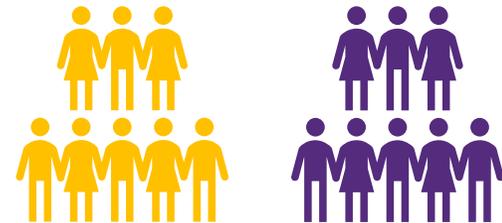
What do we know?

Stroke continues to be one of the most common causes of complex disability in adults worldwide and in Europe;

Due to the complexity of the impact and recovery, stroke affects families more broadly than many other chronic diseases;

The impact on families may result in a transformation of roles and relationships;

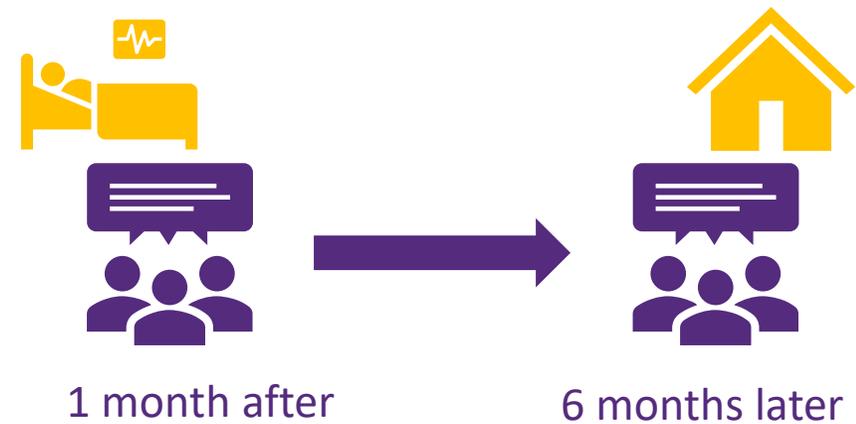
Research have tended to explore the experience of people with stroke OR caregivers/ family;



However, the **experience of stroke should not be seen as an individual phenomena.**

- To understand how Portuguese informal caregivers and their relatives who had experienced a stroke adapt to life after stroke;
- how health professionals may support their transition to home and adaptation to a changed life after stroke.

What was
our aim?



Who was involved?

People Post Stroke (8)

Age (mean): 43-79 (67)
Gender (female): 2
IB= 20-100
Ethnicity: white: 7; Black: 1
Marital status: all married
Living arrangement: all at home
Time after stroke:
1.5 month - 9 months

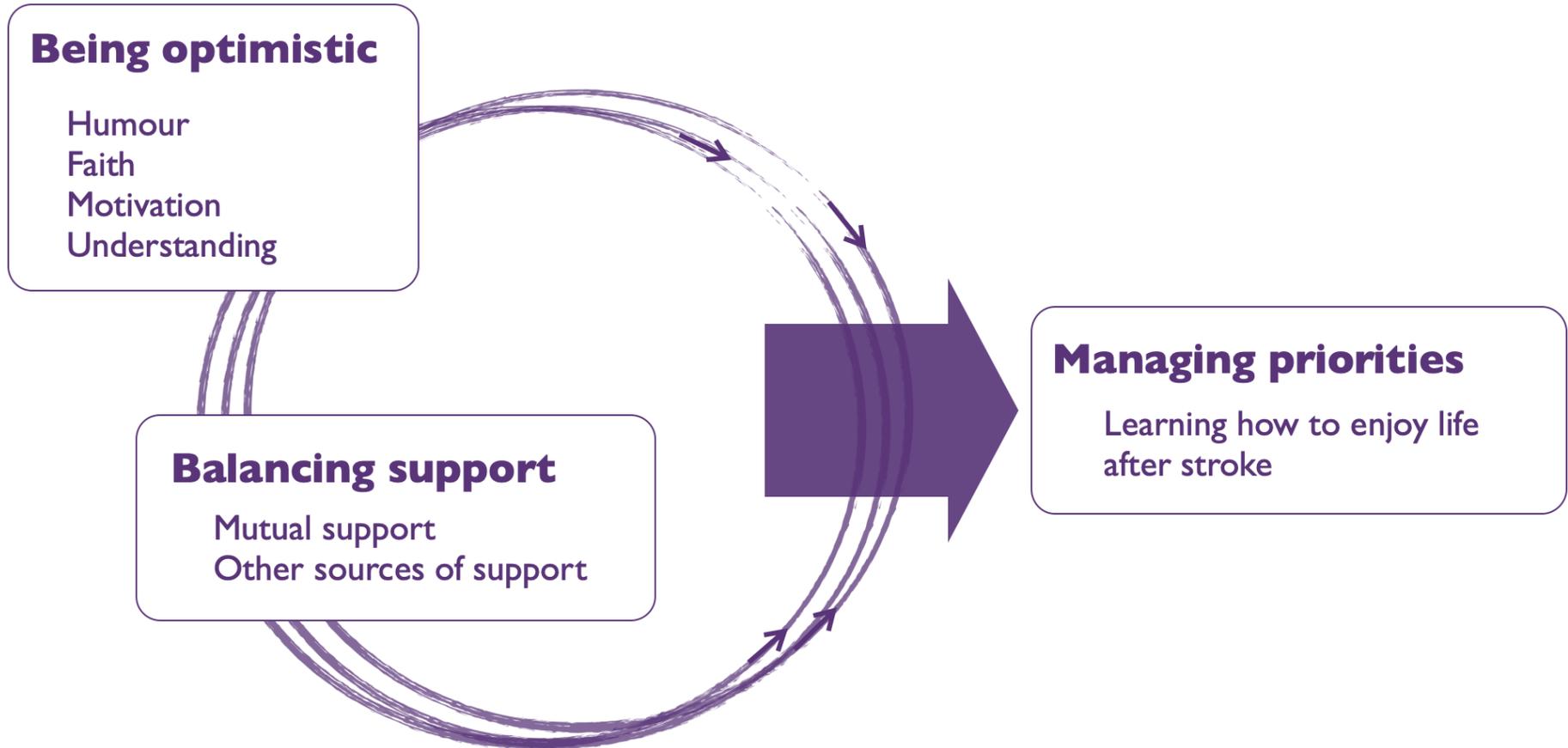
Carers (10)

Age (mean): 37-77 (56)
Gender (female): 8
Ethnicity: all white
Living situation: all living with the person post stroke
Relationship with the PPS:
- Partner: 8
- Adult child (daughter): 2

Health Professionals (6)

Profession:
- Physiotherapists: 4
- Speech therapists: 1
- Occupational Therapists: 1
Clinical setting:
- Hospital: 3
- Private setting: 2
- Non-profit rehab inst: 1

What did
we find?





Being optimistic

Humour
Faith
Motivation
Understanding

Not all carers were optimistic by nature. However, they seemed to value positive thinking as a way of moving forward.

I was always thinking what will become of us (before discharge); “if it was the other way around, I would stay there, at home, sad and upset (...) He has this very good thing; he says that we have to look ahead, there are worse cases, he has a lot of strength (...) Even when he was in the hospital, he made us laugh. I really want to believe that everything will be OK

(Carer, Triad 4, Interview 1)

Over time, the approach seemed to move from an optimistic outlook to finding positives from the new situation.



Being optimistic

Humour
Faith
Motivation
Understanding

Some participants (pws & carers), described the importance of their religious belief. Faith appeared to help maintain hope in a resumption of their lives, finding positives and accepting their destiny.

This need to accept what happened was described by some as a difficult and a gradual process, but important to maintain motivation and reduce their anger and frustration.

It's the life that no one expects... This is it, it was meant for us. Little by little I'll have to accept it (...) But I have faith that my husband will be able to walk and drive. We have faith and faith is the last thing to die

(Carer, triad 1, interview 1)

We don't do prospects for the future; we live one day at a time. We have to accept what life gives us

(Carer, triad 1, interview 2).



Being optimistic

Humour
Faith
Motivation
Understanding

Despite the initial difficulty in knowing what to do or expect, a gradual understanding about what happened, learning and developing knowledge relevant to them helped both to feel more in control and able to take decisions about their health and life.

I wasn't prepared but I understood a few things; I have an encyclopaedia (...) There it explained how to care for the person and talk to her
(Carer, triad 5, interview 1)

Over time the type of doubts seemed to change from a initial need of understanding what had happened to a later need of finding what can help them.

I would like to know if hydrotherapy could help relieving her pain
(Carer, triad 7, interview 1)

Balancing support

Mutual support
Other sources of support

Sharing losses and uncertainties between each other seemed to help both the person with stroke and the carer in perceiving a shared understanding of their needs and not feeling alone.

Reciprocal and bidirectional help appeared to allow each other to find emotional stability within the unexpected situation that affected them both.

He is always saying “I don’t want you to get upset” and then he holds me tight, he kisses me all the time (...) My husband was always someone who really cared about me... we have always been a united couple (...) I think that he feels protected and that there is someone there who worries about what he’s doing

(Carer, triad 1, interview 1)

However, over time a close relationship were not always perceived as positive and supportive by health professionals or others close to them. Emotional fragilities highlighted the importance of balancing mutuality and the support from others.



Balancing support

Mutual support

Other sources of support

We also travel because of me. I'm with her 24 hours and as you can imagine these 24 hours are not always easy. Travelling is good for me and for her. At João's home (his brother) he or his wife cooks for us... I go to the cafe and things like that. When we arrive home I already have my brain fresh and ready to start again (Carer, triad 7, interview 2)

Some participants reported trying to hide their difficulties or emotions as a way of protecting their relatives. For them, it was important to find another person to confide in.

Both people post stroke and carers considered it helpful if the health professional was patient and sensitive to their thoughts, which appeared to highlight the importance of their multiple roles, involvement and professionalism.



Managing priorities

Learning how to enjoy life
after stroke



At the time of the 2nd interview, some participants seemed to be questioning their expectations in a resumption of their previous lives. It was widely recognised that their former life had been halted and both realised the need to restart their lives and analyse future possibilities for them.

It represented a desire to stop having a life focused only on rehabilitation. It seemed to be important for both to restart making plans and adjusting them to the reality of the new situation.

We would like to have a camper van, rid myself of the house and: "look, today we live here" (...). Now it's: "look, and if we could travel tomorrow?" And we go (...) we travel a lot, we stayed 3 months in Caldas (...) and now we'll go to their house (friends' home); it's good to change for a while.

(Carer, triad 7, interview 2)

Main conclusions



- People may find several different strategies to deal with the challenges after a stroke. There are no “right” or “wrong” ways to adjust;
- Time seems to be important to understand the impact of stroke on both lives and adjust to new roles and a reality of uncertainty.
- Not every kind of support is necessarily useful for all. Health professionals may have an important role tailoring their approach to the needs of both.

THANK YOU FOR YOUR ATTENTION

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More details in:

DISABILITY AND REHABILITATION
<https://doi.org/10.1080/09638288.2020.1722263>



ORIGINAL ARTICLE



From recovery to regaining control of life – the perspectives of people with stroke, their carers and health professionals

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