Keeping Active with Texting after stroke (KATS)

Final Report

This project ran between 1st October 2020 and 28th February 2023. It was funded by the Chief Scientist Office Grant reference HIPS/19/45

Aims

When rehabilitation ends, people with stroke often feel abandoned by services and struggle to continue with prescribed rehabilitation exercises and physical activity. Supporting them in activity is important for physical health and recovery. Text messaging interventions have been used in public health to promote physical activity, but have not been widely used after stroke.

The study aims were:

- To co-design with rehabilitation professionals and people with stroke in a collaborative working group, a theoretically informed automated text messaging intervention to promote exercise and physical activity after rehabilitation (Keeping Active with Texting after Stroke - KATS).
- To assess if KATS is acceptable and feasible to people with stroke, and to examine whether it has potential to increase physical activity, confidence and stroke recovery

KEY FINDINGS

Co-design with people with stroke and experts in rehabilitation was crucial in developing KATS.

The first wave of piloting with 12 participants showed that KATS:

- Was acceptable, relevant, engaging and useable
- Brought a sense continuity from rehabilitation, and reduced feelings of abandonment

The second wave of piloting with 28 participants showed:

- Small, but non-significant positive changes in physical activity levels (measured for 24 hours per day for 7 days at baseline and follow-up)
- Statistically significant improvements in activities of daily living and mental wellbeing

WHAT DID THE STUDY INVOLVE?

The study was conducted in two phases:

Phase 1. Development of the intervention:
After reviewing the scientific literature, we held three meetings with our collaborative working group to explore possible intervention content and the fit of KATS with rehabilitation practice. We next interviewed 14 people who had completed stroke rehabilitation to explore their views on texting, KATS format and useful content. We used their feedback, behaviour change theories, and guidance on creating text messaging interventions to develop KATS, which would be delivered over 12 weeks. Our collaborative working group reviewed the draft intervention and supported revision of content and the delivery schedule.

Phase 2. Intervention Piloting: KATS was piloted in two waves, to allow for iterative refinement.

In **Wave 1** we conducted initial pilot testing with 12 people with stroke to assess accessibility and identify required adaptations. We conducted telephone interviews midway (six weeks) and at the end of the intervention (12 weeks) to inform refinements to text messages and delivery plan.

In **Wave 2** pilot testing was conducted with 28 people. To evaluate how best to measure the impact of KATS, participants wore an accelerometer (a small device to measure physical activity) for seven days at baseline and at end of the study. Twelve were interviewed at home six weeks into the intervention and all were interviewed at the end. All participants completed questionnaires on stroke recovery, activities of daily living, physical activity, wellbeing and confidence at baseline and follow-upThe study was conducted in two phases:

WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

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Phase 1 Results:

Interview participants (n=14) told us:

Usefulness of KATS:

- They had used mobile phones to text early in their recovery
- An intervention would provide continuity of support and reduce feelings of abandonment
- A texting intervention could keep people motivated

Message Terminology and Tone:

- Participants wanted an informal friendly tone that encouraged rather than dictated exercises
- Texts from a named individual would provide credibility
- Quotes from other people with stroke would provide tips, ideas for activities and encourage progress

Messages were organised into weekly blocks to:

- Guide participants to form intentions to be active, set goals, plan activity, self-monitor, cope with challenges, maintain engagement in physical activity

Stroke related texts addressed:

- Fatigue, different types of activity, regaining confidence and options for

inclement weather and boredom with exercise

To facilitate engagement texts included:

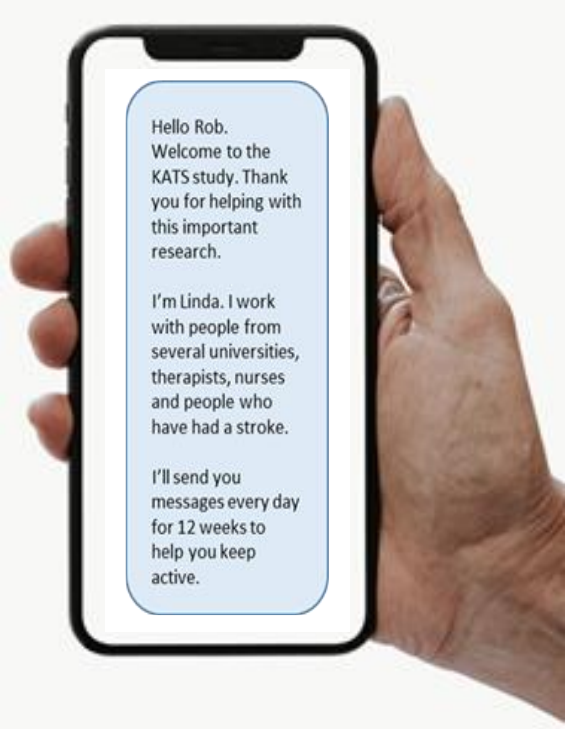
- The recipient's name, humour and trivia, prompts for relaxation and reflection

To sustain engagement:

- Participants were also asked questions to which they could respond by text

It's easy to read the texts..... My brain gets fed up trying to read it, if it's too much information (Male, 57 years)

To remind people that although they're no longer being seen, they're not lost in the system (Male, 49 years)



Phase 2. Wave 1 Piloting

Ten men and three women, average age 61 (±11.1) years and 60 (±55) weeks post-stroke living in the community were recruited. One withdrew due to ill-health. Twelve participants received 95 messages over 12 weeks. Interviews at six and 12 weeks showed that KATS was feasible to deliver, that participants found it relevant to their rehabilitation journey, that it provided continuity with rehabilitation, and aligned to the recommendations from their therapists. They reported reduced feelings of abandonment, and many identified with and took reassurance in quotes from other people with stroke.

Participants actively engaged with KATS, with all but one participant sending text messaging responses. As expected with a remotely delivered self-help intervention, engagement with the range of suggested strategies to change behaviour varied, with some engaging fully with intervention components, and others seeing texts simply as prompts or reminders. Overall, participants judged KATS to be advantageous for all people with stroke following discharge from community-based rehabilitation services.

> *I just try to involve my hand in everyday things, like taking hold of things, opening a door, putting on the shower and that sort of thing, and trying to consciously use the left hand [the hand affected by stroke] more for just doing things. That's one of the reasons I was keen to do the study, I wanted to try and keep these things going once the physio stopped. (Male, 70 years)*

> *"I've found it very, very worthwhile. I've actually surprised myself how far I've come since starting the study (...) It's built up my confidence to actually attempt other things because I feel confident in that" (Male, 56 years).*

Some participants felt KATS ended abruptly, so for Wave 2 we added two further weeks of texting, tapering message frequency to prepare participants for the intervention ending.

Phase 2: Wave 2 Piloting

Eighteen men and 13 women, average age 68 (±9.9) years and 26 (±20) weeks post-stroke took part at the end of community rehabilitation. Three were withdrawn due to unrelated illness. Twenty-eight participants received 103 messages over 14 weeks. For two, accelerometer data were not valid.

When asked, on a scale of 0-5, if the intervention was **understandable, useful, helpful, interesting or relevant**, average scores for each question were 4.3 or higher.

When asked, on a scale of 0-100, how much would you agree with the statement **"The KATS programme has helped me achieve activities that are important to me"** the average score was 73 (±19.5).

Outcome measure data must be interpreted cautiously because of high variability of scores at baseline, the small number of participants, and because there was no comparator group. We found:

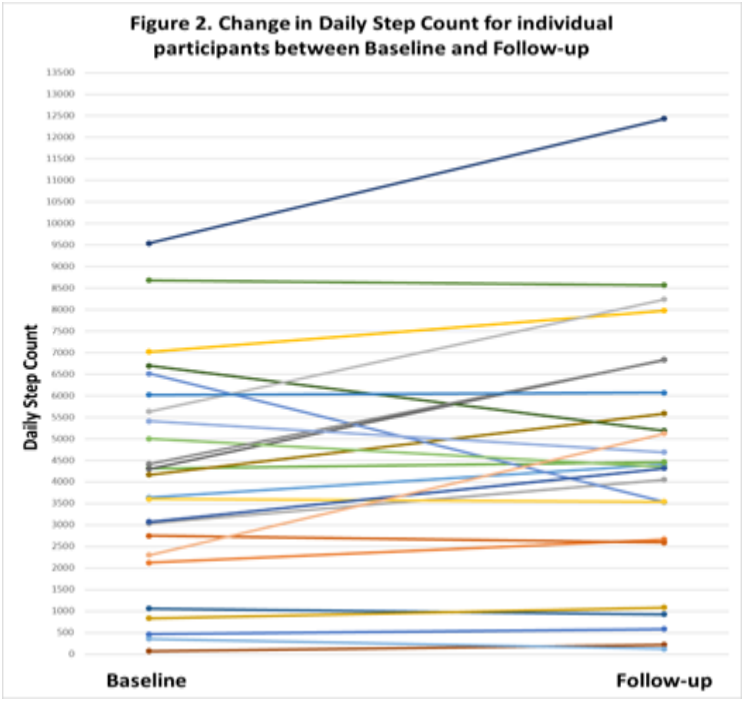
- Small improvements between baseline and follow-up were found on six questionnaires examining activities of daily living, physical activity, wellbeing, confidence post-stroke and quality of life. These improvements were statistically significant for the Nottingham Extended Activities of Daily Living Scale ($p=0.02$) and the Short Warwick-Edinburgh Mental Wellbeing Scale ($p=0.02$) (paired t-test).

- It should also be noted some participants had co-morbidities, pain or other illness or changes to their circumstances that affected their scores.

Physical Activity Assessment using accelerometers

We also measured daily step count using, the activPAL, a thigh-worn accelerometer (Figure 1). This will be the primary outcome for a future randomised controlled trial. At baseline, seven-day mean daily step-count was 4118 (±2439) and at follow-up 4475 (±2476), a non-significant difference ($p>0.05$). The high standard deviations reflect the wide range of activity levels of participants. Changes in step-count are illustrated in Figure 2, showing that most participants with more than 2000 steps at baseline improved, whereas those with fewer baseline steps who were more disabled did not change, or reduced. For some, step counts did not improve because of illness or pain, and for six participants, severely icy weather at follow-up prevented outdoor activity. These data indicate that for a future trial, participants should be able to walk at least 2000 steps per day, be well enough and sufficiently pain-free to participate.

Figure 1. The activPal



Wave 2 Interview findings.

Interviews explored participants' experiences and perceptions of acceptability and feasibility.

Attitude towards KATS Participants reported that KATS was encouraging and informative and meant they did not feel alone in their recovery. Several participants reported using intervention components and engaging with specific behaviour change techniques (e.g. goal setting, planning, monitoring). KATS often acted as a prompt for activity and encouraged participants to think about how to progress their recovery. Although KATS was not individually tailored to participants, many could discern personally relevant content. Quotes from other people with stroke were seen as motivational, modelling problem-solving, coping strategies and physical activities that improved confidence to set and achieve new goals. Text messaging was described as convenient and easily accessible. For a few, KATS came before they were ready to take part. Severe fatigue, pain, disability, poor balance and fear of falling were barriers to activity, leading to variations in participation in activity.

Engagement with KATS Participants engaged with the intervention and together sent a total of 707 responses to received texts. Only one person did not reply, and the number of responses ranged from one to 96, (average number was 25±24). Participants reported on their progress, gave details of new activities they were enjoying and made suggestions on how to keep active. Most enjoyed the daily messages and found being able to read and re-read them at any time was helpful.

I feel it has benefitted me. Keeping your mind straight to keep active instead of letting it get you down because that's a thing that could get you down some days (Female, 59)

Scottish weather again today so went shopping to Asda with my daughter, did marching up and down the living room and kitchen , sit and stands do them for 10 times at least three times a day . (Text Response, Female, 74 years)

I think that being part of the study, it's nice to think that you're not left out in this big world. My life was so different to what it was before, and it's just nice to know that there is somebody who understands that it is different. (Female, 73 years)

WHAT IMPACT COULD THE FINDINGS HAVE?

Patients: KATS was perceived as worthwhile, reducing the sense of abandonment felt after stroke rehabilitation ends, and providing ideas and motivational support for engagement with activities beneficial to recovery. We found indicators suggesting KATS may be effective in improving activities of daily living and wellbeing. Physical activity improved more for those with less disability.

Policy and Practice: Text message support at the end of rehabilitation is accessible to people with stroke and aligns with rehabilitation therapy aims. It is a feasible, acceptable and potentially effective low cost way to provide post-rehabilitation support after rehabilitation.

Research: The intervention shows promise for improving wellbeing, recovery and physical activity in people with stroke and future research will explore how to optimise those effects. The impact on post-stroke isolation and connectedness was an important finding that we will investigate further.

HOW WILL THE OUTCOMES BE DISSEMINATED?

Conferences: Intervention development findings have been presented at two national conferences (The UK Stroke Forum 2022 and the Society for Rehabilitation Research 2022). An abstract is in preparation for the World Stroke Organisation Congress, October 2023

Journal Articles: Intervention development findings are under review for Pilot and Feasibility Studies, Wave 1 findings are in submission in Health Expectations and Wave 2 findings are being written up for BMJ Open

Public and Practitioners: We will present findings in a workshop for the Scottish Stroke Allied Health Professions Forum

CONCLUSION

People with stroke could use and engage with a text messaging intervention. KATS was valued by participants and shows potential for improving wellbeing, recovery outcomes and physical activity after stroke. Participants reported increased sense of connectedness and reduced feelings of abandonment. Future studies will focus on optimising use of all intervention components within KATS before undertaking a feasibility randomised controlled trial. We will also examine specific ways to use text messaging interventions to reduce isolation and abandonment after stroke.

RESEARCH TEAM & CONTACT

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