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Barriers and facilitators to adherence to secondary stroke prevention medications after stroke: Analysis of survivors' and caregivers' views from an online stroke forum

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3 **Barriers and facilitators to adherence to secondary stroke**
4 **prevention medications after stroke: Analysis of survivors’**
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6 **and caregivers’ views from an online stroke forum**
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ABSTRACT

Objective

To identify barriers and facilitators of medication adherence in patients with stroke along with their caregivers.

Design

Qualitative thematic analysis of posts about secondary prevention medications, informed by Perceptions and Practicalities Approach.

Setting

Posts written by UK stroke survivors and their family members taking part in the online forum of the Stroke Association, between 2004 and 2011.

Participants

84 participants: 49 stroke survivors, 33 caregivers, 2 not stated, identified using the keywords 'taking medication', 'pills', 'size', 'side-effects', 'routine', 'blister' as well as secondary prevention medication terms.

Results

Perceptions reducing the motivation to adhere included dealing with medication side effects, questioning doctors' prescribing practices, and negative publicity about medications, especially in regard to statins.

Caregivers faced difficulties with ensuring medications were taken while respecting the patient's decisions not to take tablets. They struggled in their role as advocates of patient's needs with healthcare professionals. Not experiencing side effects, attributing importance to medications, positive personal experiences of taking tablets and obtaining modification of treatment to manage side effects were facilitators of adherence. Key practical barriers included difficulties with swallowing tablets, dealing with the burden of treatment and drug cost. Using medication storage devices, following routines and getting help with medications from caregivers were important facilitators of adherence.

Conclusions

An online stroke forum is a novel and valuable resource to investigate use of secondary prevention medications. Analysis of this forum highlighted significant barriers and facilitators of medication adherence faced by stroke survivors and their caregivers. Addressing perceptual and practical barriers highlighted here

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3 can inform the development of future interventions aimed at improving adherence to secondary prevention
4 medication after stroke.

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7 Abstract word count- 268

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9 Keywords: stroke, caregiver, medication adherence, online forum

10 11 12 13 Article summary

14 15 Strengths and Limitations

- 16
17 • The first study to explore and identify perceived barriers and facilitators to medication adherence
18 among users of an online stroke forum using a theoretical framework.
- 19
20 • Inclusion of caregivers offers a unique perspective for understanding of medication taking behavior in
21 patients with severe disabilities.
- 22
23 • The online forum allowed patients and caregivers to communicate in a comfortable environment
24 beyond the influence of the research team, shedding new light on factors affecting adherence to
25 secondary prevention medications.
- 26
27 • Key themes identified may be limited by the search terms used and may not provide an exhaustive list
28 of all barriers and facilitators to adherence discussed in the forum.
- 29
30 • Posts were scrutinized by a moderator prior to being published.
- 31
32 • The online forum was dated 2004-2011 and might not reflect current practice.

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53 Data sharing statement: No additional data available.

INTRODUCTION

Stroke recurrences are associated with higher disability and mortality than first time strokes,¹ and account for one third of all stroke events.² Secondary prevention medicines are considered important in reducing stroke recurrences in patient who have already experienced a stroke or transient ischaemic attack.^{3,4} However medication non-adherence is an issue known to be problematic, contributing to suboptimal health outcomes.⁵ Reported practical barriers to medication adherence after stroke include forgetting medication, difficulty swallowing tablets and difficulties handling packaged medications.⁶ A key factor decreasing patients' motivation for taking secondary prevention medications is having concerns about tablets, such as becoming dependent on them or worrying about their long term effects.⁷ Difficulties with taking medication, lack of information on stroke and medications and patient's fears of medicines are important barriers, while support from caregivers and worrying about further stroke are facilitators.⁸

Severe stroke related impairments make it difficult for survivors to participate in research. Perhaps for this reason there is little evidence available on factors affecting adherence to medications in patients with more disabling strokes (at least a third of stroke survivors).^{9,10} Studying factors affecting adherence can be difficult because of self-presentational bias, i.e. patients may perceive that a certain behaviour, e.g. adherence to treatment, is one of the duties expected of the 'good patient' and may be reluctant to admit a different behaviour^{11 12}.

Caregivers of elderly patients experience difficulties with tablet administration.¹³ As patients' dependency on caregivers for medicine taking increases, caregivers' factors also become relevant in determining patients' adherence.¹⁰ Indeed, a recent interview study by the authors¹⁴ highlighted the importance of caregivers in adherence to secondary prevention medications. Findings from another study suggest that among patients with cardiovascular disease, those with a caregiver were more likely to be adherent to medications.¹⁵ There is need to investigate adherence to secondary prevention medications after stroke avoiding self-representation biases, including patients' with severe disabilities and caregivers' factors.¹⁰ Online health forums are accessible 24/7 in the form of asynchronous communication that is convenient to the user. This medium offers anonymity and encourages honesty. Individuals with health-related difficulties can communicate in confidence about what

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3 matters to them.¹¹ TalkStroke is an online forum where survivors and their families discuss information and
4 provide support to one another. A recent study using this forum showed that a wide variety of themes were
5 discussed online, including secondary prevention medications.¹⁶ Caregiver views were well represented and
6 most of them (70%) looked after patients with severe disabilities. Among forum users who were stroke
7 survivors, 30% were suffering from severe impairments.¹⁶ Therefore data from the archives of this forum
8 have the potential to shed light on adherence issues for this hard to reach groups.¹⁷

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11 The aim of this investigation was to understand barriers and facilitators of medication adherence among
12 survivors of stroke and their caregivers' through evaluating posts written in an online stroke forum, using a
13 framework based approach.
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15 16 17 18 19 20 21 22 23 24 25 **METHODS**

26 27 28 **Design**

29 We undertook a qualitative analysis of posts to the TalkStroke online forum using the PAPA (Perceptions And
30 Practicalities Approach) theoretical framework.¹⁸ According to the framework, nonadherence is viewed as a
31 variable that can change over time and treatments. Nonadherence is known to be intentional or unintentional.
32 Unintentional adherence is linked to practical factors and resource limitation while perceptual factors or
33 beliefs affect intentional adherence, i.e. how patients consciously make decisions that influence their
34 medication taking behaviour.¹⁹ This framework posits that patients make a choice to take medication based
35 upon judgement of their personal need for the medication, relative to their concerns about the possible
36 consequences of taking it, as well as unintentional adherence.¹⁸ The PAPA approach seeks to understand
37 adherence through addressing both perceptual (beliefs and preferences) and practical (capability and
38 resources) factors which have an influence on patients commencing and continuing treatment. We searched
39 the forum archives using a set of pre-defined keywords, in order to identify barriers and facilitators of
40 adherence to secondary prevention medications. Posts were written by stroke survivors or family
41 members/caregivers.
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Setting

The analysis was performed on the archives from TalkStroke, a UK based online forum hosted by the Stroke Association website, including 22,173 posts written between 2004 and 2011 by 2,583 unique usernames.¹⁶ Talkstroke was an online resource through which stroke survivors and caregivers could seek and/or offer information and support.

Procedure and participants

A word list of unique terms of the archive file of Talkstroke was generated using AntConc3.2.4.²⁰ Terms related to secondary prevention medications were selected (e.g. Amlodipine, statin, warfarin), including misspellings (e.g. Aspirin, simvastin), brand names (e.g. Lipitor, Plavix) and drug categories (e.g. statin, diuretics etc.). Posts including any secondary prevention medication term were identified. We additionally searched the Talkstroke archive for the keywords: 'taking medication', 'pills', 'size', 'statins', 'side effects', 'capsule', 'box', 'routine', 'blister', and 'secondary prevention'. Search terms were discussed and agreed by two authors (JJ and ADS, see online supplementary figure 1).

Participants of the online forum included stroke survivors and patients talked about by caregivers, identified by usernames linked to each of the selected posts. Characteristics were retrieved from usernames, taking advantage of data from a previous study.¹⁶ Demographics are shown in table 1. All posts that were relevant for the research questions were copied and pasted into Microsoft Excel and NVivo 10 for later analysis.

Ethics

The Stroke Association gave permission to ADS to use the data for research purposes. To protect the identity and intellectual property of forum participants,²¹ we chose not to use *verbatim* quotes, despite this being normal practice in qualitative research. Instead, we used descriptions of quotes throughout the text.^{16 17} The ethical aspects of conducting research on this forum have been discussed more extensively elsewhere.¹⁶

Data Analysis

A qualitative approach using thematic analysis was undertaken to explore forum posts.²² All posts retrieved through the search terms were read by JJ to aid familiarization. To strengthen the validity of findings and ensure rigour, 50% of all posts were double-coded by ADS. Queries arising from the coding process were resolved through discussions involving a third author (SS) where necessary, until a final consensus was reached. Nvivo 10 was used to manage and organise the data. A set of codes representing key themes were initially developed from the forum posts by JJ, to represent barriers and facilitators of medication adherence. These themes were refined, and sub-themes were identified and grouped together with similar concepts. A coding framework was formed and refined further as additional themes emerged. Data saturation was reached with the recruitment of 84 individuals, beyond which no new themes emerged. Guided by the PAPA framework, we coded forum posts to identify practical and perceptual factors affecting adherence to medications. Identified themes were mapped onto the theory and sub-divided into barriers or facilitators of adherence.

Although there is evidence that inappropriate medical information or health behaviours in this online stroke forum were identified and corrected by participants in subsequent postings,¹⁶ consistent with what is reported elsewhere in a cancer patients' internet support group,²³ threads of discussions were not analysed here. Therefore self-correction received through the forum is not reported. For the purpose of this study, the term caregiver refers to family members such as spouses or children, and is not associated with paid caregivers. Online supplementary figure 1 shows the analysis pathway to reach the final number of themes.

RESULTS

Identification of posts

A search of the stroke forum resulted in 19,214 posts not associated with medication taking being excluded, leaving 2959 posts (see online supplementary figure 1). Additional analysis excluded 2527 posts not about secondary prevention medications. Of the 473 remaining posts, a further 251 were removed as being duplicate

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3 or not directly associated with medication adherence. This yielded a total of 222 posts describing barriers/
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5 facilitators of adherence to secondary prevention medication, including 162 posts by stroke survivors, 57 by
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7 caregivers and 3 by an individual whose status as a survivor or caregiver could not be identified.
8

9 10 **Characteristics of study participants**

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12 From 222 posts related to adherence to secondary prevention medications we identified 84 individuals.
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14 Approximately 60% of participants were stroke survivors posting about their own experiences with the
15
16 remainder being caregivers, predominantly sons or daughters. The age of participants ranged from 32yrs to 91
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18 yrs, male and female were similarly represented (n=40 vs n=38, see table 1). The majority of participants
19
20 experienced a stroke within 12 months of posting on the forum. Around three quarters of participants (73%)
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22 reported a stroke occurring within the last 5 years, with 44% experienced a stroke within the last 12 months.
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24 The mean number of years since stroke was 2.2 yrs for survivors and 0.8 yrs for patients talked about by
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26 caregivers. Several participants were prolific users on the forum and were instrumental in facilitating
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28 discussions and providing feedback on a considerable number of topics, offering a rich and in depth
29
30 assessment of issues raised. One forum participant wrote 37 posts about secondary prevention medications,
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32 while another 15 posts. The majority of participants (n = 44) posted only once, 19 participants twice and 6
33
34 three times. Sample characteristics are reported in table 1.
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37 Table 1 about here
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42 **Themes**

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45 The range of themes comprising barriers and facilitators of medication adherence are reported in Table 2. In
46
47 line with the PAPA approach¹⁸ these are discussed according to the following two categories.
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52 Table 2 about here
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3 **Perceptions- Necessity Beliefs and Concerns:** In this section stroke survivors' and caregivers' perceptual
4 barriers and facilitators of medication adherence are explored, according to their classifications as necessity
5 beliefs i.e. doubts about personal need for medication to maintain or improve current and future health, and
6 their concerns about secondary prevention treatment.
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11 **Practicalities- Capability and Resources:** In this section we explore barriers and facilitators that stroke
12 survivors and caregivers face around their capability of taking/giving medication and the resources available
13 to undertake such behaviour.
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18 Within each category themes are grouped into barriers and facilitators. For each of the emerging themes, when
19 relevant, caregivers' views have been reported after patients' ones.
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23 **Necessity Beliefs and Concerns - BARRIERS**

24 **Necessity Beliefs**

25 **Lack of perceived benefits of medications**

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28 A few users expressed doubts about the role of cholesterol in stroke, questioning the need for taking any
29 preventative medications at all.
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35 A male survivor acknowledged statins controlled cholesterol, but believed strokes occurred regardless
36 of cholesterol levels. He talked about the 'Cholesterol Myth' having researched the topic online and
37 admitted feeling confused about taking statins when in reality they weren't needed. [Male, age 67, age
38 at stroke 55, N.70]
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44 A female survivor read about the hype around statins and stated she still didn't have confidence in
45 them. She had read a research paper on statins suggesting they only added an extra 9 months of
46 life.[Female, age 56, age at stroke 56, N.66]
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Caregivers' related views

Caregivers struggled with their role of ensuring patients' adherence. They felt survivors' decisions about choosing or refusing medications needed to be evaluated according to patients' preferences and not just in terms of what was clinically right.

A caregiver recognized it was hard to encourage her father to take medications. He suffered many side effects which made him feel less in control so he would choose to go without tablets. She admitted it was important to have a balance regarding what the survivor wanted, considering he stated he would be happier if he felt he was in control. See concluded that patient's choice had to be respected, even if she didn't agree. [Male, age unknown, age at stroke unknown, N.46]

The fact that survivors could suffer a further stroke despite taking secondary prevention medications and following a healthy lifestyle also raised concerns around the benefits of adherence to medications.

A caregiver described how after having a first stroke, her father changed his lifestyle completely by eating well, exercising more and taking medication to control his blood pressure. However one day his BP surged suddenly and he experienced a second stroke. [Male, age unknown, time since stroke 0 yrs, N.55]

Concerns

Burden and management of medication side effects

Patients who suffered significant side effects from statins described their experiences, providing insight as to how these were affecting their medication adherence.

A female survivor experienced similar side effects from 3 different statin, despite varying dosage. She said tests confirmed this and had concluded their long term use could lead to many problems which could negatively affect quality of life [Female, age 34, age at stroke 31, N.36]

The experience of side effects led some users to alter adherence to the medications. This was done by 'making a compromise' with health professionals.

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3 A male survivor admitted being suspicious of the number and variety of pills he was dispensed. He
4 said that he had come to a compromise with his doctor about taking blood pressure tablets. He was on
5 2 tablets for blood pressure, of which one was a diuretic. Having got fed up of frequently running to
6 the toilet, he decided to check his blood pressure every day and would skip the diuretic if blood
7 pressure was fine [Male, age unknown, age at stroke unknown, N.63]
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14 To avoid side effects, some stroke survivors took the decision to reduce cholesterol through changing diet,
15 rather than medications, without mentioning whether this decision was taken with or communicated to
16 healthcare professionals.
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20 A female survivor decided to reduce her cholesterol through diet because of unpleasant side effects of
21 statins. Once symptoms disappeared, she wouldn't take the statins, but instead olive oil and a healthy
22 diet to keep her cholesterol balanced naturally. She admitted she would continue aspirin as it didn't
23 seem to cause side effects [Female, age 52, age at stroke 52, N.76]
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29 Reducing cholesterol through diet rather than medication was also suggested by GP themselves.
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32 A female survivor mentioned her cholesterol level was average. Her nurse suggested starting
33 medication but her GP was against this, saying the level could be reduced through diet and exercise
34 alone as these tablets were over prescribed. She added that statins were recommended when needed
35 because of genetic makeup [meaning familial hypercholesterolemia]. [Female, age 49, age at stroke
36 48, N.21].
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43 Depending on the exact clinical scenario, the decisions about statins in the last two posts could be medically
44 appropriate or not, i.e. act both as barrier or facilitator to adherence to secondary prevention medications. Due
45 to lack of details, no definite classification could be made. To reflect this, themes were reported under both
46 headings in Table 2, but reported only here within the results, for simplicity.
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Caregivers' related views

Caregivers assumed at times the role of advocates for their family members' suffering from medications' side effects, and reported struggling in this role. Failure to be successful in obtaining a change in treatment led some survivors to stop taking medication completely.

A female caregiver described consistently trying to have her husband's 40mg statin dosage reduced by his GP. As a result of the high dosage he was chronically tired, so he stopped taking statins. [Male, age 54, age at stroke 52, N.68]

Impact of bad press on statin

Side effects of secondary prevention medications raised important concern, and statins were frequently discussed by forum users. The bad press about statins was mentioned in relation to starting the medication and ongoing adherence. Participants discussed these concerns together with health care professionals.

A survivor wrote that despite her GP's recommendation she couldn't commence statins after reading in the press about side effects. She admitted she felt well and didn't want to jeopardise that, as she wasn't convinced she needed them. Although also her consultant disagreed with her decision and was keen for her to take them, he said she didn't necessarily have to take them. [Female, age 54, age at stroke 54, N.37]

Caregivers' related views

Reading information about statins and their side effects highlighted caregivers' struggle and made more difficult for them to help stroke survivors being adherent.

A caregiver's mother had suffered 2 mini strokes and was now prescribed both aspirin as well as pills to lower cholesterol but was refusing to take these as she had read in the press about the bad side effects they caused [Female, age unknown, age at stroke unknown, N.74]

Questioning prescribing practices

Disappointment was expressed when practitioners failed to start/change secondary prevention medications when the survivor judged their current treatment to be inadequate.

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3 A survivor described feeling let down as he requested changes in medications because he didn't feel
4 they [aspirin and clopidogrel] were beneficial. He'd lost confidence in the health care system after
5 visiting several consultants and being sent home with unchanged medications. [Male, age 43, age at
6 stroke 41, N.20]
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11 Or when the medication prescribed to the stroke survivor was perceived as incorrect:
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14 A survivor recalled being on 75mg of aspirin as well as beta blockers. He felt that if he had been
15 taking warfarin instead of aspirin, he may not have suffered another stroke [Male, age 67, age at
16 stroke 55, N.82]
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21 Receiving conflicting advice on medication practices caused further uncertainty and confusion, which might
22 have indirectly affected adherence to secondary prevention medications.
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25 A survivor suffered increased bleeding while on warfarin was taken off it. He suffered another stroke
26 shortly after, and was put back on warfarin for the bleeding to begin again. He felt confused at being
27 told to stay on warfarin to avoid a potentially serious stroke. [Male, aged 72, age at stroke 72, N.10]
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35 Caregivers' related views

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37 Caregivers too raised concerns about GPs prescribing, principally statins, for financial rather than medical
38 reasons, which could indirectly affect adherence, especially in patients suffering from statin side effects.
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42 A caregiver (sister) suggested that GPs shouldn't be paid for prescribing statins and that the decision
43 should be based on clinical judgement alone. She suggested medication could be overprescribed as a
44 result for financial reasons [Gender and age unknown, age at stroke unknown, N.78]
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49 Caregivers' role as advocates for their family members came up in questioning prescribing practices,
50 highlighting caregivers' awareness of guidelines and difficulties at times with obtaining treatment
51 modifications on patients' behalf. (The cost of atorvastatin has dropped since, so this post does not reflect
52 current practice).
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3 A caregiver recommended being firm with GPs about being put on atorvastatin if simvastatin was not
4 tolerated, as atorvastatin was a bit more expensive but recommended by NICE guidelines as an
5 alternative [Gender and age unknown, age at stroke unknown, N.18].
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10 11 **Necessity Beliefs and Concerns – FACILITATORS**

12 Necessity beliefs

13 **Attributing importance to secondary prevention medications**

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16 The importance of secondary prevention medication in reducing the risk of a stroke event was acknowledged
17 by forum users. Prioritising secondary prevention tablets over other types of medications highlighted the
18 significance survivors attached to adherence to these medications. These posts were often written in reply to
19 users complaining of medication side effects.
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26 A female survivor commented that it was better to take a few extra tablets from the GP than to
27 experience another stroke. Tablets were provided to prevent a further stroke, and she stressed that they
28 shouldn't be stopped except on professional advice [Female, age 51, age at stroke 51, N.17]
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34 Another survivor mentioned feeling reassured by medications, particularly warfarin.
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38 A female survivor mentioned that although she had suffered 2 strokes in the previous year, none had
39 occurred since commencing warfarin. She felt reassured about taking warfarin and she was now
40 worried about coming off the medication as she had already experienced flashing in her left eye since
41 she had started to be weaned off the drug [Survivor, female, age 42, age at stroke 42, N.35]
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47 Caregivers' related views

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49 Caregivers also recognized the importance of medications and the need to continue taking tablets despite
50 experiencing side effects. The importance of only stopping medication on GP's advice was highlighted.
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54 A caregiver admitted that because of side-effects her husband had voluntarily come off all the
55 medication he was taking, except for aspirin which he continued to use. She said they had agreed to
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3 this together with the GP and stressed the importance of doing so before stopping tablets. [Male, age
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5 54, age at stroke 52, N.68]
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10 11 **Experiencing consequences of non-adherence as driver of necessity beliefs**

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13 Experiencing the consequences of medication nonadherence after having another stroke reinforced necessity
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15 beliefs about secondary prevention medications.
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18 A survivor who had already suffered 2 strokes admitted it was impossible to ever fully recover from
19
20 the stroke experience. He said after his first stroke he was prescribed tablets he didn't take and after
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22 suffering the second stroke he realised this was a big mistake. [Male, age 67, age at stroke 55, N.82]
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25 A survivor refused statins after her first stroke because of side effects. However, after suffering a
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27 second one she was now worried enough to take them. [Survivor, female, age 68, age at stroke 67,
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29 N.14]
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31 Caregivers' related views

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34 Caregivers generally held strong beliefs about the need for secondary prevention medications.
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37 A caregiver (husband) advised that if patients don't take medications they're likely to become worse.
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39 He was amazed about how many people choose not to take their tablets, perhaps half of them, and few
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41 even did so when they knew they had a meeting with the consultant in the coming weeks. [Female,
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43 age 46, age at stroke 46, N.12]
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45
46 A caregiver (daughter) mentioned that her father wasn't taking medication routinely. He had had a
47
48 massive stroke just a few weeks earlier. She wanted to say to forum users that if stroke survivors
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50 follow a healthy lifestyle and are strict with medications, then there is no reason why a major stroke
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52 could not be prevented. [Male, age 55, age at stroke 55, N.6]
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Concerns

Absence of side effects

Survivors who did not experience medication side effects generally felt that taking medication was a positive preventive measure against stroke. Although threads of discussion were not analysed, these posts often were written in reply to users who complained about suffering from side effects.

A male survivor advised it was better taking tablets than risking another mini-stroke. He had a severe stroke himself and was prescribed aspirin and simvastatin. He never experienced side effects and also knew others on the same statin who didn't experience any either. [Male age 67, age at stroke 63, N.52]

Successfully managing side effects

Forum users reported changes in secondary prevention medications being made by the health professionals to counteract negative side effects, which helped adherence.

A male survivor described that on a dosage of 8mg of warfarin he started to suffer migraines and bleeding, leading him to refuse the drug. After further conclusive tests, the consultant decided to take him off warfarin as he was taking persantin, which never gave him a headache or nosebleed. He acknowledged warfarin was an important drug, but didn't suit everyone. [Male, age 49, age at stroke 49, N.47]

Some survivors reflected on the role of GPs in their adherence. They felt that the GP's role was to provide advice. Getting support from family in medication related decisions was considered important.

A male survivor agreed to stop taking a blood pressure tablet with his doctor because of intolerable side effects, and his wife being a nurse made it easier. He felt strongly that doctors are there to advise not instruct. [Male, age unknown, age at stroke unknown, N.63]

Doctors' and patients' perseverance in modifying medications was important to achieve optimal treatment.

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3 A male survivor admitted taking up to 7 different blood pressure tablets and that it was unusual for a
4 stroke patient to only need a few. He recommended going back to the GP as necessary to keep
5 changing tablets until the right combination was found [Male, age 52, age at stroke 52, N.64]
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9 10 Caregiver view

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12 Reduction of tablet dosage by doctors to eliminate side effects was reported as a successful strategy to deal
13 with side effects and aid adherence.
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17 A female caregiver described her husband suffering from considerable side effects from simvastatin
18 40mg but when the GP changed to atorvastatin at a lower dose of 10mg he was able to cope. [Male,
19 age 54, age at stroke 54, N.49]
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24 25 26 **Trusting healthcare professionals**

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29 Healthcare professionals had an important role in patients' trust in secondary prevention medications and
30 consequently adherence.
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34 A survivor described how he trusted his vascular surgeon who had changed his medication from
35 warfarin to aspirin and statin. The survivor was happy to take aspirin and felt it would be good to
36 continue as the surgeon also took it regularly, concluding it must be beneficial [Survivor, male, age
37 35, age at stroke 34, N.71]
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45 **Capability and resources - BARRIERS**

46 47 **Difficulties taking tablets**

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49 Swallowing difficulties were reported when taking tablets, especially in relation to the medication
50 dipyridamole, due to its size.
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3 A male survivor described ‘swallow panic’, i.e. fear of choking when trying to take Dipyridamole
4 capsules. The user admitted it took around 3 months before he got over that. [Male, age 67, age at
5 stroke 55, N.70]
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10 Size of tablets also caused handling difficulties due to stroke related impairments.

11
12 A survivor agreed with another user about the problem with the size of dipyridamole tablets, which
13 were getting stuck in the pill box organizer. [Female, age 46, age at stroke 45, N.30]
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16 17 18 19 Caregivers’ related views

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21 Taking multiple tablets also contributed to treatment burden experienced by caregivers. One caregiver
22 described how this added to the survivor’s episodic refusal to take any medications.
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25
26 A caregiver was asking advice on encouraging medication taking. He said his mother was on multiple
27 tablets, up to 4 times a day, but was now refusing to take any at all and this did upset him. Persuading
28 her to continue taking the most important tablets had taken hours to do. [Male, age 77, age at stroke
29 77, N.9]
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35 Another practical difficulty was dealing with routine appointments which were considered burdensome,
36 resulting in the survivors being non-adherent to medications.
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39
40 A caregiver (wife) described how her husband was adamant that he was not prepared to take statins
41 because he didn’t have the time to keep going back to the GP for check-ups. The caregiver admitted
42 feeling helpless. [Male, age 55, age at stroke 55, N.24]
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48 Caregivers of patients with severe disabilities such as aphasia and inability to communicate made their job of
49 ensuring patients’ adherence a difficult experience.
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53 A caregiver said she couldn’t imagine what a stroke survivor was going through, with her mother
54 unable to communicate following a stroke. She described her mother having difficulties with
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3 medications caused by previous changes in treatment. She felt her mother was giving up and wanted
4 advice on dealing with aphasia. [Caregiver-daughter, age 52, age at stroke 47, N.54]
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9 Using Dosette boxes was at times a struggle for survivors with severe disabilities, and a source of worry for
10 caregivers.
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12
13 A caregiver mentioned that despite using a nomad tray, tablets were still being taken from the wrong
14 day with several days' worth of tablets being taken in a single day. His father in law often didn't take
15 the time to work out the days or to look at the calendar [Male, age unknown, age at stroke unknown,
16 N.40]
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22 Another caregiver admitted having to seek advice on the best way to manage the stroke survivor's
23 medications.
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25
26 A caregiver said he went to the pharmacist and spent half an hour chatting about medications after
27 which he bought a flip top multi-coloured medication box labeled with the days and doses. He
28 admitted it took him a while to establish the best way to fill the box without getting confused,
29 eventually filling it a tablet at a time across the entire week, instead of a day at a time. (Male, age 82,
30 age at stroke 82, N. 57)
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38 **Cost of medications**

39 Survivors' highlighted difficulties faced with meeting the cost of stroke medications.
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42 A female survivor described being prescribed both aspirin and simvastatin that she had to pay for. She
43 reported having to take out a credit card to pay for her medication as she was unable to work and did
44 not have any money coming or any benefits. [Female, age 59, age at stroke 59, N.72]
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Capability and resources – FACILITATORS

Storage devices for medication management

Stroke survivors reported benefits from using medication aids including pill-boxes and medication wallets to facilitate medication taking behavior. These devices ensured the appropriate medication was being taken at the right time, while also allowing monitoring when boxes needed to be re-filled.

A survivor agreed the storage box was useful to view medication and her husband didn't have to keep asking her whether she had taken her tablets as he could also see. She admitted to being irritated at being constantly asked. The box helped her also with not running out of medications as she filled it weekly and could tell when it was time for a repeat prescription. [Female, age 46, age at stroke 45, N.30]

Caregivers' related views

Following instructions was considered helpful in facilitating day to day medicine taking. Keeping track of medicines that had been taken was suggested as a method of ensuring good adherence.

A caregiver (son) described making a note on the pill box asking the survivor to turn it over after taking the pills as this would mean the morning pills were now taken. A second instruction invited the survivor to do the same when taking the evening tablet. He suggested to forum users that a simple chart tracking when each medication was taken was also helpful. [Caregiver-son, age 82, age at stroke 82, N.57]

Good medication taking routines

Linking daily tablet use to an everyday activity or placing tablets in a specific location which then acted as a cue to take the medication was described as helpful by several users.

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2
3 A survivor suggested using a white board and having method in place helped. She remembered taking
4 her own medications through repetition or linking tablet use to another everyday activity [Female, age
5 54, age at stroke 46, N.19]
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9 10 Caregivers' related views

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12 Caregivers also played a key role in medication routines when survivors couldn't remember to take tablets.

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15 A caregiver (wife) described regularly giving her husband his medication because stroke had caused
16 short term memory loss and he would forget them or sometimes take them over again. She admitted
17 she was now in total control of his medication which was fine because she was a nurse with
18 experience of this. [Female, Age 46, age at stroke 40, N.5]
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29 **DISCUSSION**

30 31 **Summary of main findings**

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33 Data from an online forum provided a rich source of information, illuminating on practical and perceptual
34 barriers and facilitators to adherence to secondary prevention medications in stroke survivors and their
35 caregivers. These data highlight several points. Concerns around the bad press on statins could result in stroke
36 survivors being cautious about commencing/keep taking the medication, and opting for a change in diet as an
37 alternative (potentially a not medically appropriate decision and without healthcare professionals' support).
38 Survivors expressed concerns about being prescribed medications they considered inappropriate, questioned
39 GPs' motivation to prescribe medications and at times realised when prescribing mistakes occurred.
40 Caregivers themselves reported some doubts about the effectiveness of tablets and difficulties in ensuring
41 good medication adherence, while recognising that it is ultimately a survivor's decision whether or not to take
42 medication, particularly when suffering from side effects. Indeed, not experiencing side effects from
43 secondary prevention medications was an important facilitator of adherence. Health professionals successfully
44 modifying treatment to manage side effects and awareness that not everyone suffers from side effects were
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3 reported as increasing the motivation to take secondary prevention treatment. Believing that medications
4 reduced stroke risk, feeling reassured by taking secondary prevention treatment and experiencing another
5 cerebrovascular event as consequence of nonadherence were important drivers of necessity beliefs and
6 supported adherence.
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11 Practical barriers included difficulties swallowing capsules, burden of multiple medications, stroke-related
12 communication impairments (e.g. aphasia) causing patients' confusion with any treatment changes,
13 difficulties meeting medication costs and with managing storage devices. Caregivers' posts greatly
14 contributed to these data. They reported that improved patients' adherence was linked to using medications
15 storage devices, getting help from pharmacists in organising medicines, assuming full control of their family
16 members' medication taking, and having previous experience and knowledge about medications and their
17 administration.
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29 **Strengths and limitations**

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32 This study has a number of strengths. Firstly, the method of data collection where descriptions by forum users
33 capture unprompted thoughts, is unlikely to be affected by self-presentation bias. Information comes from
34 patients over a wide geographical area and include people who might not take part in traditional research
35 because of severe disabilities, communication impairments or in the case of caregivers, because of lack of
36 time.¹¹ The forum creates a natural environment facilitating exchange in opinions and in-depth discussions
37 around several topics including secondary prevention medications. The important presence of caregivers in
38 online discussions is a further strength, offering a unique viewpoint on survivor's medication taking behavior.
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46 These findings however should be interpreted with caution. A key limitation of this research was that forum
47 data was from the years 2004- 2011 and therefore the findings reported here may not reflect current practice in
48 primary care. Lack of details about the underlying clinical scenarios described in some of the posts made
49 difficult classifying emerging themes as barriers or facilitators to adherence. In addition, barriers and
50 facilitators were limited to those identified from the pre-defined search criteria. Different keywords may have
51 uncovered additional barriers to medication adherence we failed to identify. All forum posts were examined
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3 by a moderator prior to being published online which may have restricted the views of some users. Finally,
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5 with the majority of forum users under the age of 70, it is possible that this method of data collection
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7 overlooks a significant proportion of the older stroke population.
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10 11 12 **Comparisons with existing literature** 13

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15 Our investigation shed light on the significance stroke survivors and caregivers attributed to the bad
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17 press on statins, which impacted on their adherence. This is in agreement with a recent investigation
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19 concluding that negative statin related news stories was associated with early discontinuation of statin and
20
21 increased risk of death by cardiovascular disease.²⁴ Furthermore, people already taking statin were found to
22
23 be more likely to stop this medication following high media coverage.²⁵
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26 Findings from the present study also highlight the difficulties experienced by stroke survivors using
27
28 blister packaged medication and dosette boxes, despite at the same time outlining their benefit in terms of
29
30 adherence. Evidence from a systematic review has demonstrated significant improvement in adherence for
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32 those in the group using reminder packaging²⁶ as well as using pill boxes and blister packs in packaging
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34 interventions in cardiovascular disease²⁷ while the use of reminder packaging may be a simple way of
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36 improving adherence to medication²⁸ With older people know to experience difficulties taking medication,
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38 developing interventions that seek to combine the use of medication management devices with caregiver co-
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40 operation may be one way of addressing the practical challenges they face.
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45 Barriers to caring for the stroke survivor post hospital discharge have included a lack of collaboration with the
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47 healthcare team and a lack of community support for the caregiving role²⁹ as well as insufficient knowledge
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49 and skills to care for the survivor in the home.³⁰ We described in this study the struggle caregivers face in their
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51 role as advocate of patients, on one side engaging with healthcare professionals for ensuring that
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53 recommended secondary prevention treatment is received, and on the other side wanting to support and
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55 respect patients' decisions about taking or not medications. Caregivers facing this dilemma could benefit from
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3 greater support by GPs and pharmacists. Caregivers could play an important role in bridging the gap between
4 health professional and stroke survivor in primary care and deserve more research and clinical attention.
5 Developing interventions that seek to encourage active caregivers' engagement in stroke survivors' -
6 healthcare professionals' shared-decision making can help to address more comprehensively barriers to
7 adherence as well as deliver a care program tailored to the individual needs of patients.⁸
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16 Barriers highlighted here are in line with those reported by another qualitative study, where negative or
17 erroneous beliefs about tablets, doubts around the effectiveness of medication and concerns about the
18 consequences of not taking tablets were associated with being low adherers.³¹ Greater emphasis on informing
19 stroke survivors and caregivers about secondary prevention medications in primary care is needed. In a recent
20 randomised trial evaluating an educational package for stroke survivors and caregivers, participants who
21 received tailored information along with verbal reinforcement reported a greater satisfaction with medical and
22 practical services.³²
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31 Survivors' concerns around the need for secondary prevention medication may reflect a wider pattern of
32 misunderstanding about the benefits of such drugs. In an assessment of attitudes towards taking cardiovascular
33 medications, caution expressed around medications was linked with how great their risk to health was
34 perceived to be.³³ A meta-analysis examining the necessity-concerns framework across a range of conditions
35 found that experiencing the consequences of nonadherence reinforced the subsequent need to take tablets,
36 acting as a driver of medication adherence,³⁴ in agreement to what reported in this study by both stroke
37 survivors and caregivers.
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46 Although statins are known to reduce the risk of stroke by as much as 25%,³⁵ benefits are undermined by
47 suboptimal adherence. In a previous examination on patient perspectives around statin therapy, compliance
48 with statins was associated with information provided during the practitioner consultation as well as the
49 beliefs about cholesterol and current health status³⁶. This concurs with the findings in our study. In a recent
50 investigation exploring nonadherence and patient's perceptions towards statins, it was found that up to three
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3 quarters of participants doubted the necessity of statins, lacked knowledge about this medication, and
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5 concerns around side effects were significantly associated with intentional nonadherence.³⁷
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8 In this online forum we found evidence that stroke survivors establish routines and use cues to facilitate
9
10 medication taking. This is in agreement with the findings from a pilot trial in which a plan to establish
11
12 medication routine resulted in significantly greater adherence among survivors.^{38,39} Providing support to
13
14 establish medication taking routines particularly among older patients with stroke can be beneficial.⁴⁰

15
16 Challenges to adherence with warfarin therapy, including beliefs about the need for this treatment have been
17
18 highlighted previously, suggesting the benefit of a more collaborative patient - practitioner approach, focusing
19
20 on education around anticoagulant therapy.⁴¹
21

22 23 24 25 **Implications for clinical practice** 26

27
28 These findings demonstrate the need to address identified barriers to adherence to secondary prevention
29
30 medications within clinical practice. Improving patient- and caregiver-practitioner communication through
31
32 more effective clinical consultations has the potential to benefit patients and encourage a greater
33
34 understanding of the importance of secondary prevention medications. This approach could contribute not
35
36 only to shape patients' beliefs about medications but also to improve confidence around taking them.

37
38 Challenging negative medication beliefs and adopting practices that implement simple medication taking
39
40 routines and appropriate use of tablet storage devices can increase adherence and ultimately improve health
41
42 outcomes.^{40,41}
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45 Both primary and secondary healthcare professionals should seek to engage the family of survivors and their
46
47 support network to challenge concerns around taking tablets, offer reassurance on the benefits of medications,
48
49 discuss the need of treatment in light of side effects, and even support patients' informed decision to refuse
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51 medications.
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54 Interventions using 'expert patients' or 'expert caregivers' providing support to stroke survivors and
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56 caregivers in the primary care setting hold potential.¹⁵
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3 Internet fora for patients with stroke provide a potentially important resource through which the attitudes of
4 survivors and their caregivers towards medication use can be better understood.
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8 9 **Future research**

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12 Our study suggests that caregivers play an important role in bridging the gap between patient and practitioner
13 with regard to informing and facilitating the medication taking process. Future research should therefore
14 further explore their role in stroke survivors' medication taking and systematically incorporate them in
15 adherence interventions.
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20 Given the strong focus of forum users on statins, understanding why stroke survivors choose not to take
21 statins as prescribed and suggesting to healthcare professionals effective ways of dealing with this issue
22 should be a key focus for research in this area. With adverse events the most common reason for poor
23 adherence to statin therapy, improved patient understanding of this medication through greater
24 communication with the practitioner can help to address ongoing concerns.⁴²
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29 Future interventions should aim at further improving medication taking routines after stroke, using cues to
30 prompt tablet taking. Advances in technology could facilitate delivery of such interventions. One novel
31 approach to improving adherence particularly with regards to multiple medications is the use of fixed-dose
32 combination therapy 'polypill approach'.⁴³ Indeed a recent systematic review of barriers and facilitators of
33 adherence to secondary prevention medications within cardiovascular disease found fixed dose combination
34 (FDC) therapy to be an important facilitator associated with high adherence.³⁸
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46 **Conclusion**

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49 This study identified barriers and facilitators to medication adherence for stroke through analysing data from
50 an online forum using a framework approach. Developing interventions which build on these results according
51 to the framework has the potential to improve medication adherence and ultimately reduce the burden of
52 stroke. Greater efforts are needed to meet the growing challenges faced by stroke survivors and their
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3 caregivers and to enable primary care clinicians to effectively address the burden of nonadherence to
4
5 secondary prevention medications.
6

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9
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11
12 forum.
13

14 Competing Interests

15
16
17 None declared
18

19 Author/s contribution

20
21
22 ADS conceived of the study, is the Chief Investigator, contributed to the data analysis and commented on the
23
24 manuscript. JM is a co-investigator on the study, wrote and commented on the manuscript. SS is a co-
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26 investigator on the study, wrote and commented on the manuscript. JJ contributed to the study design,
27
28 conducted the data analysis and prepared the manuscript for submission. All authors agreed on the final draft
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30 of the submitted manuscript.
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Sample characteristics	N	Median Range
Total participants identified in posts	84	
Number of posts in the forum/ participant		16 (1-4932)
Number of posts about secondary prevention medications/ participant		1 (1-37)
Age at stroke		
Survivor		50 (32-72)
Patient by caregiver		66 (46-91)
Gender		
Male -Survivor	20	
Female- Survivor	26	
Not known - Survivor	3	
Male -Patient talked about by caregiver	20	
Female - Patient by caregiver*	12	
Unknown gender and unknown identity	3	
Identity person posting		
Stroke survivor	49	
Caregiver	33	
Not known	2	
Years since stroke		
(0-12 mths)	37	
(1-5 yrs)	25	
(6-10 yrs)	4	
(11-15 yrs)	2	
(15+ yrs)	1	
Unknown	15	
Caregiver identity		
Daughter /son	20	
Spouse	9	
Other (/in law/ sister)	3	
Unknown	1	

Legend: * Patient talked about by a caregiver

Table 1. Characteristics of online Talkstroke participants as identified in the study posts

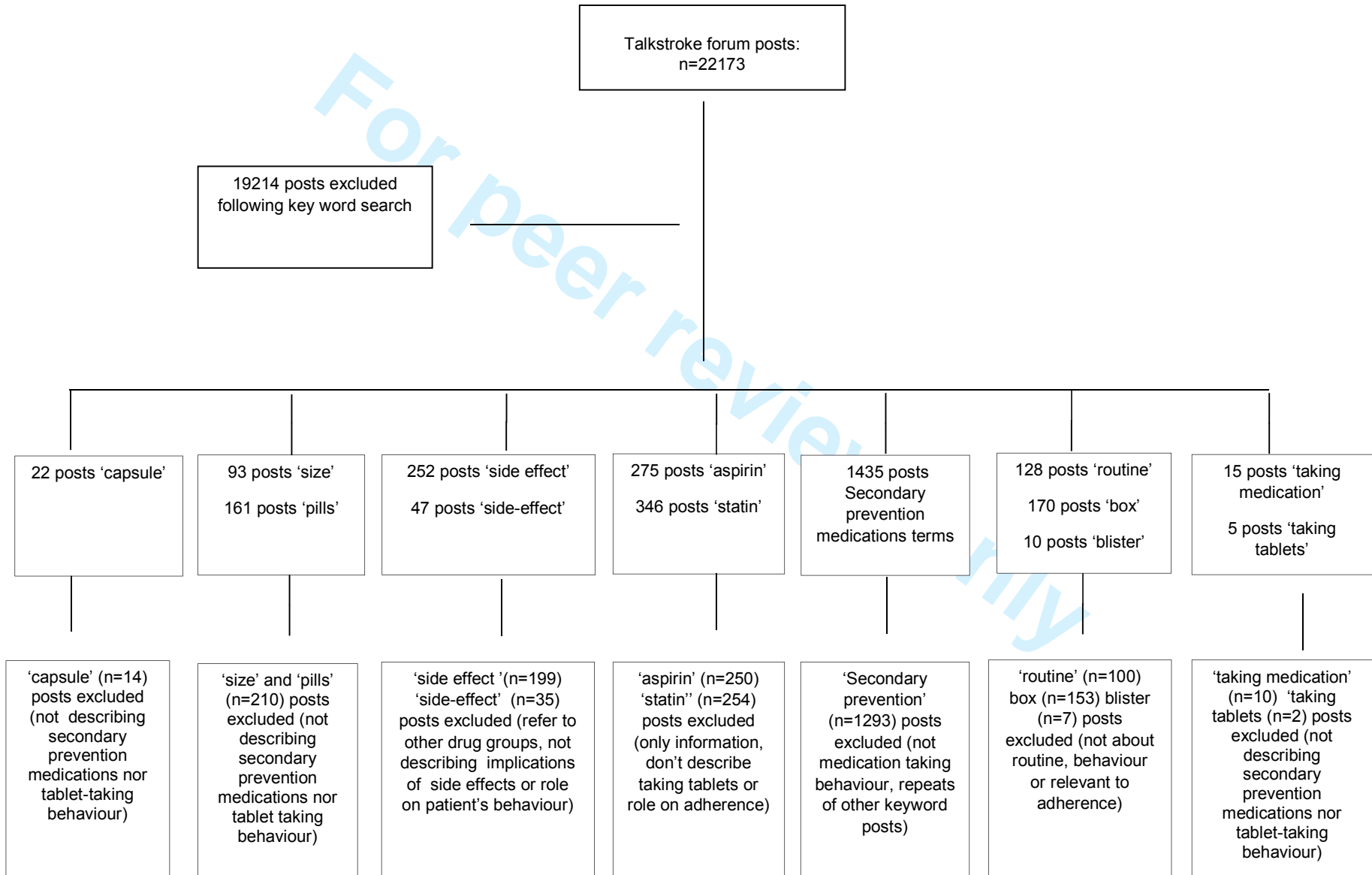
Table 2. Key themes highlighting survivors' and caregivers' barriers and facilitators to adherence to secondary prevention medications classified according to perceptions and practicalities.

Perceptions –Necessity Beliefs and Concerns	
Barriers	Facilitators
<p><u>Necessity beliefs</u></p> <p>Lack of perceived benefits of medication</p> <ul style="list-style-type: none"> • Questioning the effectiveness of secondary prevention medications in preventing stroke recurrence. • Considering statins detrimental to health and not effective. <p><u>Caregiver</u></p> <ul style="list-style-type: none"> • <i>Valuing adherence but recognising that is the choice of the patient to take tablets.</i> • <i>Realising that stroke could still occur despite taking secondary prevention medication.</i> <p><u>Concerns</u></p> <p>Burden and management of medication side effects</p> <ul style="list-style-type: none"> • Experiencing statins side effects and considering they have potential to worsen quality of life. • Intentionally missing medication to manage side effects. • Changing diet/lifestyle as alternative to taking medication to reduce side effects.* • Healthcare professionals recommending diet and exercise to reduce cholesterol instead of taking statins.* 	<p><u>Necessity beliefs</u></p> <p>Attributing importance to secondary prevention medications</p> <ul style="list-style-type: none"> • Recognising taking tablets as important to prevent stroke recurrence. • Feeling reassured by taking secondary prevention medications. • Experiencing consequences of nonadherence (a further stroke) as driver of necessity beliefs. <p><u>Caregiver</u></p> <ul style="list-style-type: none"> • <i>Feeling secondary prevention medications are important and should only be stopped in consultation with the GP.</i> • <i>Holding strong beliefs about the need for secondary prevention medications.</i> • <i>Experiencing consequences of nonadherence as driver of necessity beliefs.</i> <p><u>Concerns</u></p> <ul style="list-style-type: none"> • Not experiencing medication side-effects. • Awareness that not all patients are affected by side effects of medications. • Changing diet/lifestyle as alternative to taking medication to

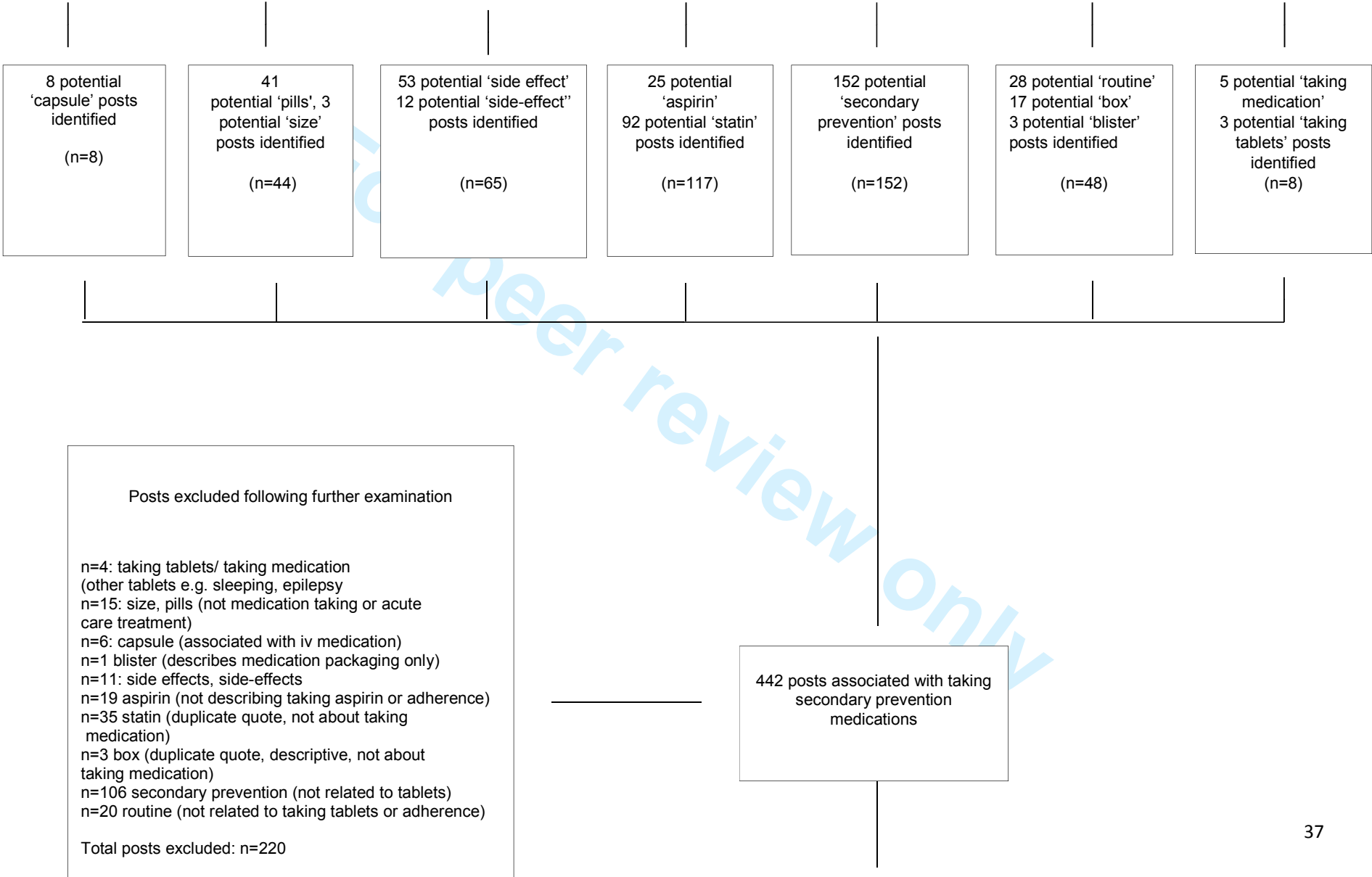
<p><u>Caregiver</u></p> <ul style="list-style-type: none"> Struggling to raise issues about side effects of statins with healthcare professionals and obtaining changes in treatment when patients find it unsuitable. <p>Impact of bad press on statins</p> <ul style="list-style-type: none"> Being extra-cautious about commencing statins for fear of side effects <p><u>Caregiver</u></p> <ul style="list-style-type: none"> Struggling to ensure patients' adherence to statins in face of bad press. <p>Questioning prescribing practices</p> <ul style="list-style-type: none"> Being disappointed as medications considered ineffective were not changed by GPs. Having concerns around incorrect medications being prescribed. Receiving conflicting information about medications. <p><u>Caregiver</u></p> <ul style="list-style-type: none"> Worrying about medications being prescribed for financial reasons or guidelines over clinical judgement Experiencing difficulties with asking GPs to prescribe alternative tablets as current ones considered unsuitable. 	<p>reduce side effects.*</p> <ul style="list-style-type: none"> Healthcare professionals recommending diet and exercise to reduce cholesterol instead of taking statins.* <p>Successfully managing side effects</p> <ul style="list-style-type: none"> Obtaining changes in treatment from healthcare professionals until side effects are manageable <p><u>Caregiver</u></p> <ul style="list-style-type: none"> Obtaining changes in treatment from healthcare professionals until side effects are manageable <p>Trusting healthcare professionals</p> <ul style="list-style-type: none"> Perceiving medications to be beneficial as secondary healthcare professional also taking it.
<p>Practicalities- Capability and Resources</p>	
<p>Barriers</p>	<p>Facilitators</p>
<p>Difficulties taking tablets</p> <ul style="list-style-type: none"> Swallowing medication capsules, especially big size ones. Experiencing difficulties with handling medications due to size and stroke related physical impairments. <p><u>Caregiver</u></p> <ul style="list-style-type: none"> Experiencing frustration with burden of multiple medications and episodic patients' refusal of medications. Experiencing frustration at patient refusal to take statins and attend routine medication appointment. 	<p>Storage devices for medication management</p> <ul style="list-style-type: none"> Using pill box: helping seeing the correct medication was taken and when prescription needed to be renewed. <p><u>Caregiver</u></p> <ul style="list-style-type: none"> Using pill-boxes to provide written instruction to patients or keeping a note of tablets taken.

<ul style="list-style-type: none"> • <i>Experiencing difficulties when helping patients with aphasia taking tablets in the context of changes in treatment.</i> • <i>Experiencing frustration at patients failing to keep up with refilling prescriptions.</i> • <i>Being worried about patients not using the pillbox correctly.</i> <p>Cost of medications</p> <ul style="list-style-type: none"> • Struggling to meet the costs of secondary prevention medications. 	<p>Good medication taking routines</p> <ul style="list-style-type: none"> • Linking tablet use to an everyday activity to facilitate medication taking behaviour. <p><u>Caregiver</u></p> <ul style="list-style-type: none"> • <i>Assuming control of medication when patients have problems with short term memory and reminding when tablets have to be taken.</i>
<p>Legend: Statements in italics refer to caregiver themes. * Because of missing details of the underlying clinical scenario, these themes could act both as barriers or facilitators to adherence to secondary prevention medications, therefore have been reported under both headings.</p>	

Figure 1. Analysis strategy to identify study posts



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Posts analysed: thematic analysis on themes classified as barriers or facilitators of medication adherence.

n= 4: Taking medication/ taking tablets

n= 29: Size, pills

n= 2: Capsule

n= 2: Blister

n= 54: Side effects, side-effects

n= 6: Aspirin

n= 57: Statin

n= 14: Box

n= 46: Secondary prevention medication terms

n= 8: routine

Total posts included: n= 222

Thematic analysis: Development of themes associated with barriers and facilitators of medication adherence

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For peer review only

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Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description	
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	N/A
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	BSc, MSc
3.	Occupation	What was their occupation at the time of the study?	Research Assistant/ PhD Student
4.	Gender	Was the researcher male or female?	Male
5.	Experience and training	What experience or training did the researcher have?	JJ is a researcher with experience in undertaking qualitative research.
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	N/A
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	N/A
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	N/A
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis,</i>	Thematic analysis: Pg. 7

No	Item	Guide questions/description	
		<i>ethnography, phenomenology, content analysis</i>	
Participant selection			
10.	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>	All users of an online forum who posted comments on medication adherence were eligible for inclusion Pg. 6
11.	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>	Participants were not directly approached. Information they submitted to an online forum was analysed Pg. 6
12.	Sample size	How many participants were in the study?	84 Pg. 8
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	N/A
Setting			
14.	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	Data was collected from an online forum electronically and remotely. Pg. 6
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	N/A
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	Gender, age, stroke survivor/ caregiver, years since stroke occurred Pg. 8
Data collection			
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	N/A
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	N/A
19.	Audio/visual recording	Did the research use audio or visual recording to	N/A

No	Item	Guide questions/description	
		collect the data?	
20.	Field notes	Were field notes made during and/or after the interview or focus group?	N/A
21.	Duration	What was the duration of the interviews or focus group?	N/A
22.	Data saturation	Was data saturation discussed?	Yes Pg. 7
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	2 authors contributed to the coding process. JJ coded all of the forum posts. 20% of posts were independently coded by ADS. Pg. 7
25.	Description of the coding tree	Did authors provide a description of the coding tree?	Table 2 reports all the themes that were identified and coded from the data. Pg. 33
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes were generated from the data Pg. 9-21, 33
27.	Software	What software, if applicable, was used to manage the data?	Microsoft Excel, Nvivo qualitative analysis software Pg. 6
28.	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>	Yes, however, for ethical reasons and to protect participant confidentiality quotes were presented as descriptions, rather

No	Item	Guide questions/description	
			than quotes literally extracted from the online forum. Participants were only identified by a unique number. Pg. 6
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes Pg. 7-21
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes Pg. 7-21
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes. Key themes and sub-themes are reported. Restrictions on word count prevented themes being discussed extensively Pg. 7-21

BMJ Open

Barriers and facilitators to adherence to secondary stroke prevention medications after stroke: Analysis of survivors' and caregivers' views from an online stroke forum

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2017-016814.R1
Article Type:	Research
Date Submitted by the Author:	17-May-2017
Complete List of Authors:	JAMISON, JAMES; UNIVERSITY OF CAMBRIDGE, Public Health and Primary Care Sutton, Stephen; University of Cambridge, Public health and Primary Care Mant, Jonathan; University of Cambridge, Public Health and Primary Care De Simoni, Anna; Queen Mary University of London, Centre for Primary Care and Public Health
Primary Subject Heading:	Cardiovascular medicine
Secondary Subject Heading:	Qualitative research
Keywords:	STROKE MEDICINE, Caregiver, Medication adherence, Online forum

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Manuscripts

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6 **2 prevention medications after stroke: Analysis of survivors’**
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10 **3 and caregivers’ views from an online stroke forum**
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ABSTRACT28
29 Objective

30 To identify barriers and facilitators of medication adherence in patients with stroke along with their
31 caregivers.

32 Design

33 Qualitative thematic analysis of posts about secondary prevention medications, informed by Perceptions and
34 Practicalities Approach.

35 Setting

36 Posts written by UK stroke survivors and their family members taking part in the online forum of the Stroke
37 Association, between 2004 and 2011.

38 Participants

39 84 participants: 49 stroke survivors, 33 caregivers, 2 not stated, identified using the keywords 'taking
40 medication', 'pills', 'size', 'side-effects', 'routine', 'blister' as well as secondary prevention medication terms.

41 Results

42 Perceptions reducing the motivation to adhere included dealing with medication side effects, questioning
43 doctors' prescribing practices, and negative publicity about medications, especially in regard to statins.

44 Caregivers faced difficulties with ensuring medications were taken while respecting the patient's decisions not
45 to take tablets. They struggled in their role as advocates of patient's needs with healthcare professionals. Not
46 experiencing side effects, attributing importance to medications, positive personal experiences of taking
47 tablets and obtaining modification of treatment to manage side effects were facilitators of adherence. Key
48 practical barriers included difficulties with swallowing tablets, dealing with the burden of treatment and drug
49 cost. Using medication storage devices, following routines and getting help with medications from caregivers
50 were important facilitators of adherence.

51 Conclusions

52 An online stroke forum is a novel and valuable resource to investigate use of secondary prevention
53 medications. Analysis of this forum highlighted significant barriers and facilitators of medication adherence
54 faced by stroke survivors and their caregivers. Addressing perceptual and practical barriers highlighted here

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3 55 can inform the development of future interventions aimed at improving adherence to secondary prevention
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5 56 medication after stroke.

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7 57 Abstract word count- 268

8 58
9 59 Keywords: stroke, caregiver, medication adherence, online forum
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13 62 Article summary

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15 63 Strengths and Limitations

- 16
17 64 • The first study to explore and identify perceived barriers and facilitators to medication adherence
18 65 among users of an online stroke forum using a theoretical framework.
19
20 66 • Inclusion of caregivers offers a unique perspective for understanding of medication taking behavior in
21 67 patients with severe disabilities.
22
23 68 • The online forum allowed patients and caregivers to communicate in a comfortable environment
24 69 beyond the influence of the research team, shedding new light on factors affecting adherence to
25 70 secondary prevention medications.
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27 71 • Key themes identified may be limited by the search terms used and may not provide an exhaustive list
28 72 of all barriers and facilitators to adherence discussed in the forum.
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30 73 • Posts were scrutinized by a moderator prior to being published.
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32 74 • The online forum was dated 2004-2011 and might not reflect current practice.
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42 76 Funding: ADS is funded by a NIHR Academic Clinical Lectureship. The views expressed are those of the
43 77 author(s) and not necessarily those of the NHS, the NIHR or the Department of Health. James Jamison was
44 78 supported by a research grant from The Stroke Association and the British Heart Foundation: TSA
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48 79 BHF 2011/01
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53 82 Data sharing statement: No additional data available.
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INTRODUCTION

Stroke recurrences are associated with higher disability and mortality than first time strokes,¹ and account for one third of all stroke events.² Secondary prevention medicines are considered important in reducing stroke recurrences in patient who have already experienced a stroke or transient ischaemic attack.^{3,4} However medication non-adherence is an issue known to be problematic, contributing to suboptimal health outcomes.⁵ Reported practical barriers to medication adherence after stroke include forgetting medication, difficulty swallowing tablets and difficulties handling packaged medications.⁶ A key factor decreasing patients' motivation for taking secondary prevention medications is having concerns about tablets, such as becoming dependent on them or worrying about their long term effects.⁷ Difficulties with taking medication, lack of information on stroke and medications and patient's fears of medicines are important barriers, while support from caregivers and worrying about further stroke are facilitators.⁸

Severe stroke related impairments make it difficult for survivors to participate in research. Perhaps for this reason there is little evidence available on factors affecting adherence to medications in patients with more disabling strokes (at least a third of stroke survivors).^{9,10} Studying factors affecting adherence can be difficult because of self-presentational bias, i.e. patients may perceive that a certain behaviour, e.g. adherence to treatment, is one of the duties expected of the 'good patient' and may be reluctant to admit a different behaviour, or reactivity bias, i.e. if patients are aware that their adherence is being monitored, this might increase adherence simply by drawing attention to it.¹¹ In a recent investigation, De Simoni and colleagues used an online forum to explore adherence to inhaler treatment in asthma adolescents according to a framework, gaining fresh insights on factors affecting adherence in this patients' group.¹²

Our analysis differs from previous adherence literature by assessing survivors and caregivers attitudes to medication adherence from a viewpoint that has not been previously explored. The online forum offers users the opportunity to discuss issues around medication that may be considered sensitive and which they may be less willing to address through traditional face to face approaches.

Caregivers of elderly patients experience difficulties with tablet administration.¹³ As patients' dependency on caregivers for medicine taking increases, caregivers' factors also become relevant in determining patients'

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2
3 112 adherence.¹⁰ Indeed, a recent interview study by the authors¹⁴ highlighted the importance of caregivers in
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5 113 adherence to secondary prevention medications. Findings from another study suggest that among patients with
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7 114 cardiovascular disease, those with a caregiver were more likely to be adherent to medications.¹⁵ There is a
8
9 115 need to investigate adherence to secondary prevention medications after stroke avoiding self- presentational
10
11 116 and reactivity biases, including patients' with severe disabilities and caregivers' factors.¹⁰ Online health
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13 117 forums are accessible 24/7 in the form of asynchronous communication that is convenient to the user. This
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15 118 medium offers anonymity and encourages honesty. Individuals with health-related difficulties can
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17 119 communicate in confidence about what matters to them.¹¹ TalkStroke is an online forum where survivors and
18
19 120 their families discuss information and provide support to one another. Recent investigations using this forum
20
21 121 showed that a wide variety of themes were discussed online, including secondary prevention medications.¹⁶
22
23 122 ¹⁷Caregiver views were well represented and most of them (70%) looked after patients with severe disabilities.
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25 123 Among forum users who were stroke survivors, 30% were suffering from severe impairments.¹⁶ Therefore
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27 124 data from the archives of this forum have the potential to shed light on adherence issues for these hard to
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29 125 reach groups.^{18 17}
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32 126 The aim of this investigation was to understand barriers and facilitators of medication adherence among
33
34 127 survivors of stroke and their caregivers through evaluating posts written in an online stroke forum, using a
35
36 128 framework based approach.

129 130 **METHODS**

131 132 **Design**

133 We undertook a qualitative analysis of posts to the TalkStroke online forum using the PAPA (Perceptions And
134 Practicalities Approach) theoretical framework.¹⁹ According to the framework, nonadherence is viewed as a
135 variable that can change over time and treatments. Nonadherence is known to be intentional or unintentional.
136 Unintentional adherence is linked to practical factors and resource limitation, e.g. forgetting to take
137 medications because of lack of prompting or experiencing difficulties with swallowing tablets. Perceptual
138 factors or beliefs affect intentional adherence, i.e. how patients consciously make decisions that influence their

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3 139 medication taking behaviour.²⁰ This occurs when patients deliberately choose not to follow recommendations
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5 140 and where beliefs about medications influence motivation to start and continue treatment. The PAPA
6
7 141 framework was chosen as it is specifically designed to identify and classify factors affecting adherence to
8
9 142 medications. Results have the potential to inform the development of behavioural interventions aimed at
10
11 143 improving adherence and their subsequent evaluation according to causal pathways. The framework posits
12
13 144 that patients make a choice to take medication based upon judgement of their personal need for the
14
15 145 medication, relative to their concerns about the possible consequences of taking it.¹⁹ The PAPA approach
16
17 146 seeks to understand adherence through addressing both perceptual (beliefs and preferences) and practical
18
19 147 (capability and resources) factors which have an influence on patients commencing and continuing treatment.
20
21 148 We searched the forum archives using a set of pre-defined keywords, in order to identify barriers and
22
23 149 facilitators of adherence to secondary prevention medications. Posts were written by stroke survivors or
24
25 150 family members/caregivers.

27 28 151 **Setting**

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31 152 The analysis was performed on the archives from TalkStroke, a UK based online forum hosted by the Stroke
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33 153 Association website, including 22,173 posts written between 2004 and 2011 by 2,583 unique usernames.¹⁶
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35 154 Talkstroke was an online resource through which stroke survivors and caregivers could seek and/or offer
36
37 155 information and support. Forum users could discuss any topics, develop their own conversation threads and
38
39 156 there was no restriction on the subject discussed. Participants could read the subject of the thread being
40
41 157 discussed and decide whether they wished to contribute. Differentiating survivors and caregivers was done by
42
43 158 reading the text of the post: survivors talked in first person about themselves, while caregivers were talking
44
45 159 about a stroke survivor in the third person, e.g. 'my father had a stroke'. Stroke survivors with severe
46
47 160 disabilities were amongst the users of the forum. Caregivers could register as users independently from
48
49 161 patients. 60% of users were in fact caregivers.¹⁶ We acknowledge that some caregivers could have assisted
50
51 162 patients in writing their posts, though we do not have data to quantify these occurrences.

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165 **Procedure and participants**

166 A word list of unique terms of the archive file of Talkstroke was generated using AntConc3.2.4.²¹ Terms
167 related to secondary prevention medications were selected (e.g. Amlodipine, statin, warfarin, ramipril),
168 including misspellings (e.g. Aspirin, simvastin), brand names (e.g. Lipitor, Plavix) and drug categories (e.g.
169 statin, diuretics, blood pressure medicines etc.). Posts including any secondary prevention medication term
170 were identified. We additionally searched the Talkstroke archive for the keywords: ‘taking medication’,
171 ‘pills’, ‘size’, ‘statins’, ‘side effects’, ‘capsule’, ‘box’, ‘routine’, ‘blister’, and ‘secondary prevention’. These
172 keywords were lay terms used by patients with stroke and their caregivers when talking about adherence to
173 secondary prevention medications as emerged from the transcripts of a previous interview study by the
174 authors¹⁴. The aim of the interviews was exploring stroke survivors’ and caregivers’ views around barriers
175 and facilitators of adherence to secondary prevention medications in general practice. Search terms were
176 discussed and agreed by two authors (JJ and ADS, see online supplementary file 1).

177 Participants of the online forum included stroke survivors and patients talked about by caregivers, identified
178 by usernames linked to each of the selected posts. Characteristics were retrieved from usernames, taking
179 advantage of data from a previous study.¹⁶ Demographics are shown in table 1. All posts that were relevant
180 for the research questions were copied and pasted into Microsoft Excel and NVivo 10 for later analysis.

181 **Ethics**

182 The Stroke Association gave permission to ADS to use the data for research purposes. To protect the identity
183 and intellectual property of forum participants,²² we chose not to use *verbatim* quotes, despite this being
184 normal practice in qualitative research. Instead, we used descriptions of quotes throughout the text.^{16 18}
185 Paraphrasing of the text reflected as closely as possible the original posts and was agreed amongst authors to
186 minimise interpretation bias. The ethical aspects of conducting research on this forum have been discussed
187 more extensively elsewhere.¹⁶

189 **Data Analysis**

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3 190 A qualitative approach using thematic analysis was undertaken to explore forum posts.²³ All posts retrieved
4
5 191 through the search terms were read by JJ to aid familiarization. To strengthen the validity of findings and
6
7 192 ensure rigour, 50% of all posts were double-coded by ADS. Throughout the process the authors checked the
8
9 193 coding structure obtained to ensure a high level of agreement in coding was maintained. Once completed,
10
11 194 coding were compared and the intercoder reliability was measured. The kappa score was 80%. Queries
12
13 195 arising from the coding process were resolved through discussions involving a third author (SS) where
14
15 196 necessary, until a final consensus was reached. Nvivo 10 was used to manage and organise the data. A set of
16
17 197 codes representing key themes were initially developed from the forum posts by JJ, to represent barriers and
18
19 198 facilitators of medication adherence. These themes were refined, and sub-themes were identified and grouped
20
21 199 together with similar concepts. A coding framework was formed and refined further as additional themes
22
23 200 emerged. Data saturation was reached with the recruitment of 84 individuals, beyond which no new themes
24
25 201 emerged. Guided by the PAPA framework, we coded forum posts to identify practical and perceptual factors
26
27 202 affecting adherence to medications. Identified themes were mapped onto the theory and sub-divided into
28
29 203 barriers or facilitators of adherence.

30
31
32 204 While we were unable to ask questions to clarify themes, users could participate in forum discussions they
33
34 205 were interested in, offering insights on barriers and facilitators to adherence that may be beyond the reach of
35
36 206 interviews. A previous investigation comparing an online forum with qualitative interviews concluded that the
37
38 207 forum could provide useful data for qualitative health research.²⁴

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41 208 Although there is evidence that inappropriate medical information or health behaviours in this online
42
43 209 stroke forum were identified and corrected by participants in subsequent postings,¹⁶ consistent with what is
44
45 210 reported elsewhere in a cancer patients' internet support group,²⁵ threads of discussions were not analysed
46
47 211 here. Therefore self-correction received through the forum is not reported. For the purpose of this study, the
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49 212 term caregiver refers to family members such as spouses or children, and is not associated with paid
50
51 213 caregivers. Online supplementary file 1 shows the analysis pathway to reach the final number of themes.

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RESULTS**217 Identification of posts**

218 A search of the stroke forum resulted in 19,214 posts not associated with medication taking being excluded,
219 leaving 2959 posts (see online supplementary file 1). Additional analysis excluded 2527 posts not about
220 secondary prevention medications. Of the 473 remaining posts, a further 251 were removed as being duplicate
221 or not directly associated with medication adherence. This yielded a total of 222 posts describing barriers/
222 facilitators of adherence to secondary prevention medication, including 162 posts by stroke survivors, 57 by
223 caregivers and 3 by an individual whose status as a survivor or caregiver could not be identified.

224 Characteristics of study participants

225 From 222 posts related to adherence to secondary prevention medications we identified 84 individuals.
226 Approximately 60% of participants were stroke survivors posting about their own experiences with the
227 remainder being caregivers, predominantly sons or daughters. The age of participants ranged from 32yrs to 91
228 yrs, male and female were similarly represented (n=40 vs n=38, see table 1). The majority of participants
229 experienced a stroke within 12 months of posting on the forum. Around three quarters of participants (73%)
230 reported a stroke occurring within the last 5 years, with 44% having had a stroke within the previous 12
231 months. The mean number of years since stroke was 2 yrs 2 months for survivors and 10 months for patients
232 talked about by caregivers. Several participants were prolific users on the forum and were instrumental in
233 facilitating discussions and providing feedback on a considerable number of topics, offering a rich and in
234 depth assessment of issues raised. One forum participant wrote 37 posts about secondary prevention
235 medications, while another 15 posts. The majority of participants (n = 44) posted only once, 19 participants
236 twice and 6 three times. Sample characteristics are reported in table 1.

237 Table 1 about here

238

239 Themes

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3 241 The range of themes comprising barriers and facilitators of medication adherence are reported in Table 2. In
4
5 242 line with the PAPA approach¹⁹ these are discussed according to the following two categories.

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9
10 244 Table 2 about here

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13 245 **Perceptions- Necessity Beliefs and Concerns:** In this section perceptual barriers and facilitators of
14
15 246 medication adherence in stroke survivors and caregivers are explored, according to their classifications as
16
17 247 necessity beliefs i.e. doubts about personal need for medication to maintain or improve current and future
18
19 248 health, and their concerns about secondary prevention treatment.

20
21
22 249 **Practicalities- Capability and Resources:** In this section we explore barriers and facilitators that stroke
23
24 250 survivors and caregivers face around their capability of taking/giving medication and the resources available
25
26 251 to undertake such behaviour.

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28 252 Within each category themes are grouped into barriers and facilitators. For each of the emerging themes, when
29
30 253 relevant, caregivers' views have been reported after patients' ones.

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33 254 **Perceptions of secondary prevention medications**

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36 255 **Necessity beliefs and concerns**

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38 256 **Treatment Necessity**

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40 257 **Lack of perceived benefits of medications**

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45 259 **Doubts about high cholesterol as risk factor for stroke**

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47 260 A few users expressed doubts about the role of cholesterol in stroke, questioning the need for taking any
48
49 261 preventative medications at all.

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54 263 *A male survivor acknowledged statins controlled cholesterol, but believed strokes occurred regardless*
55
56 264 *of cholesterol levels. He talked about the 'Cholesterol Myth' having researched the topic online and*

265

described feeling confused about taking statins when in reality they weren't needed. [Male, age 67,

age at stroke 55, N.70]

268

269 **Doubts about the added benefit of statins**

270 Doubts were also expressed about the benefits statin added to long term health outcomes

271 *A female survivor read about the hype around statins and stated she still didn't have confidence in*

272 *them. She had read a research paper on statins suggesting they only added an extra 9 months of*

273 *life. [Female, age 56, age at stroke 56, N.66]*

274 Caregivers' related views

275 **Respecting patient's medication choice**

276 Caregivers struggled with their role of ensuring patients' adherence. They felt survivors' decisions about

277 choosing or refusing medications needed to be evaluated according to patients' preferences and not just in

278 terms of what was clinically right.

279 *A caregiver recognized it was hard to encourage her father to take medications. He suffered many*

280 *side effects which made him feel less in control so he would choose to go without tablets. She said it*

281 *was important to have a balance regarding what the survivor wanted, considering he stated he would*

282 *be happier if he felt he was in control. See concluded that patient's choice had to be respected, even if*

283 *she didn't agree. [Male, age unknown, age at stroke unknown, N.46]*

284

285 **Awareness of stroke recurrences despite medications**

286 The fact that survivors could suffer a further stroke despite taking secondary prevention medications and

287 following a healthy lifestyle also raised concerns around the benefits of adherence to medications.

288 *A caregiver described how after having a first stroke, her father changed his lifestyle completely by*

289 *eating well, exercising more and taking medication to control his blood pressure. However one day*

1
2
3 290 *his BP surged suddenly and he experienced a second stroke. [Male, age unknown, time since stroke 0*
4
5 291 *yrs, N.55]*

7 292 **Attributing importance to medications**

8
9 293

10 294 **Secondary prevention medications are essential to prevent stroke recurrences**

11
12 295 The importance of secondary prevention medication in reducing the risk of a stroke event was acknowledged
13
14 296 by forum users. Prioritising secondary prevention tablets over other types of medications highlighted the
15
16 297 significance survivors attached to adherence to these medications. These posts were often written in reply to
17
18 298 users complaining of medication side effects.

19
20
21 299 *A female survivor commented that it was better to take a few extra tablets from the GP than to*
22
23 300 *experience another stroke. Tablets were provided to prevent a further stroke, and she stressed that*
24
25 301 *they shouldn't be stopped except on professional advice [Female, age 51, age at stroke 51, N.17]*

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27 302

28 29 303 **Secondary prevention medications offer reassurance**

30
31 304 Another survivor reported feeling reassured by medications, particularly warfarin.

32
33 305 *A female survivor mentioned that although she had suffered 2 strokes in the previous year, none had*
34
35 306 *occurred since commencing warfarin. She felt reassured about taking warfarin and she was now*
36
37 307 *worried about coming off the medication as she had already experienced flashing in her left eye since*
38
39 308 *she had started to be weaned off the drug [Survivor, female, age 42, age at stroke 42, N.35]*

40
41 309

42 43 310 **Experiencing the consequences of non-adherence improves adherence**

44
45 311 Experiencing the consequences of medication nonadherence after having another stroke reinforced necessity
46
47 312 beliefs about secondary prevention medications.

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51 313 *A survivor who had already suffered 2 strokes acknowledged it was impossible to ever fully recover*
52
53 314 *from the stroke experience. He said after his first stroke he was prescribed tablets he didn't take and*

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3 315 *after suffering the second stroke he realised this was a big mistake. [Male, age 67, age at stroke 55,*

4
5 316 *N.82]*

6
7
8 317 *A survivor refused statins after her first stroke because of side effects. However, after suffering a*

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10 318 *second one she was now worried enough to take them. [Survivor, female, age 68, age at stroke 67,*

11
12 319 *N.14]*

13
14 320 Cargivers' related views

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16 321 **Not taking secondary prevention medications is risky**

17
18 322 Caregivers generally held strong beliefs about the need for secondary prevention medications.

19
20 323 *A caregiver (husband) advised that if patients don't take medications they're likely to become worse.*

21
22 324 *He was amazed about how many people choose not to take their tablets, perhaps half of them, and few*

23
24 325 *even did so when they knew they had a meeting with the consultant in the coming weeks. [Female, age*

25
26 326 *46, age at stroke 46, N.12]*

27
28
29 327 *A caregiver (daughter) mentioned that her father wasn't taking medication routinely. He had had a*

30
31 328 *massive stroke just a few weeks earlier. She wanted to say to forum users that if stroke survivors*

32
33 329 *follow a healthy lifestyle and are strict with medications, then there is no reason why a major stroke*

34
35 330 *could not be prevented. [Male, age 55, age at stroke 55, N.6]*

36
37 331

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39 332 **Concerns**

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41 334

Management of medication side effects

42
43 335 **Suffering from side effects contributes to suboptimal adherence**

44
45
46 336 The experience of side effects led some users to intentionally alter adherence to the medications. This was

47
48 337 done by 'making a compromise' with health professionals.

49
50 338 *A male survivor described being suspicious of the number and variety of pills he was dispensed. He*

51
52 339 *said that he had come to a compromise with his doctor about taking blood pressure tablets. He was*

53
54 340 *on 2 tablets for blood pressure, of which one was a diuretic. Having got fed up of frequently running*

1
2
3 341 *to the toilet, he decided to check his blood pressure every day and would skip the diuretic if blood*
4
5 342 *pressure was fine [Male, age unknown, age at stroke unknown, N.63]*
6
7

8 343 **Lifestyle changes versus taking secondary prevention medications**

9
10 344 To avoid side effects, some stroke survivors took the decision to reduce cholesterol through changing diet,
11
12 345 rather than medications, without mentioning whether this decision was taken with or communicated to
13
14 346 healthcare professionals. However reducing cholesterol through diet rather than medication was recommended
15
16 347 by the GP also.
17
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19 348

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21
22 349 *A female survivor decided to reduce her cholesterol through diet because of unpleasant side effects of*
23
24 350 *statins. Once symptoms disappeared, she wouldn't take the statins, but instead olive oil and a healthy*
25
26 351 *diet to keep her cholesterol balanced naturally. She said she would continue aspirin as it didn't seem*
27
28 352 *to cause side effects [Female, age 52, age at stroke 52, N.76]*
29

30 353

31
32 354 *A female survivor mentioned her cholesterol level was average. Her nurse suggested starting*
33
34 355 *medication but her GP was against this, saying the level could be reduced through diet and exercise*
35
36 356 *alone as these tablets were over prescribed. She added that statins were recommended when needed*
37
38 357 *because of genetic makeup [meaning familial hypercholesterolemia]. [Female, age 49, age at stroke*
39
40 358 *48, N.21].*
41

42 359 Depending on the exact clinical scenario, the decisions about statins in the last two posts could be medically
43
44 360 appropriate or not, i.e. act both as barrier or facilitator to adherence to secondary prevention medications. Due
45
46 361 to lack of details, no definite classification could be made. To reflect this, themes were reported under both
47
48 362 headings in Table 2, but reported only here within the results, for simplicity.
49

50 363 Caregivers' related views

51 364 **Caregiver difficulties as advocates of stroke survivors with healthcare professionals**

1
2
3 365 Caregivers assumed at times the role of advocates for their family members suffering from the side effects of
4
5 366 medication and reported struggling in this role. Failure to be successful in obtaining a change in treatment led
6
7 367 some survivors to stop taking medication completely.

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9
10 368 *A female caregiver described consistently trying to have her husband's 40mg statin dosage reduced*
11
12 369 *by his GP. As a result of the high dosage he was chronically tired, so he stopped taking statins. [Male,*
13
14 370 *age 54, age at stroke 52, N.68]*

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Impact of bad press on statin

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Influence of side effects on taking medicines

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22 378

Side effects of secondary prevention medications raised important concern, and statins were frequently

23 379

discussed by forum users. The bad press about statins was mentioned in relation to starting the medication and

24 380

ongoing adherence. Participants discussed these concerns together with health care professionals.

25 381

A survivor wrote that despite her GP's recommendation she couldn't commence statins after reading

26 382

in the press about side effects. She said she felt well and didn't want to jeopardise that, as she wasn't

27 383

convinced she needed them. Although also her consultant disagreed with her decision and was keen

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for her to take them, he said she didn't necessarily have to take them. [Female, age 54, age at stroke

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54, N.37]

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Caregivers' related views

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Bad press making harder for caregivers to encourage adherence

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Reading information about statins and their side effects highlighted caregivers' struggle and made it more

33 389

difficult for them to help stroke survivors be adherent.

34 390

A caregiver's mother had suffered 2 mini strokes and was now prescribed both aspirin as well as pills

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to lower cholesterol but was refusing to take these as she had read in the press about the bad side

36 392

effects they caused [Female, age unknown, age at stroke unknown, N.74]

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5 394

Questioning prescribing practices

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Problems with obtaining appropriate secondary prevention medication treatment

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9 396
10
11 397 Disappointment was expressed when practitioners failed to start/change secondary prevention medications12
13 398 when the survivor judged their current treatment to be inadequate.14
15 39916
17 400 *A survivor described feeling let down as he requested changes in medications because he didn't feel*18
19 401 *they [aspirin and clopidogrel] were beneficial. He'd lost confidence in the health care system after*20
21 402 *visiting several consultants and being sent home with unchanged medications. [Male, age 43, age at*22
23 403 *stroke 41, N.20]*24
25 404

Concerns around incorrect prescribing

26
27 405
28
29 406 This was also apparent when the prescribed medication was perceived as being incorrect.30
31 40732
33 408 *A stroke survivor recalled being on 75mg of aspirin as well as beta blockers, however, his nephew*34
35 409 *who was a consultant surgeon, suggested that had he been taking warfarin instead of the aspirin he*36
37 410 *may not have suffered a second stroke [Male, age 67, age at stroke 55, N.82]*38
39 411

Inconsistent advice about medications prescribed

40
41 412
42
43 413 Receiving conflicting advice on medication practices caused further uncertainty and confusion, which might44
45 414 have indirectly affected adherence to secondary prevention medications.46
47 415 *A survivor suffered increased bleeding while on warfarin was taken off it. He suffered another stroke*48
49 416 *shortly after, and was put back on warfarin for the bleeding to begin again. He felt confused at being*50
51 417 *told to stay on warfarin to avoid a potentially serious stroke. [Male, aged 72, age at stroke 72, N.10]*52
53 418

1
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3 419 Caregivers' related views

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5 420 **Questioning GP's motivation to prescribe**

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8 421 Caregivers too raised concerns about GPs prescribing, principally statins, for financial rather than medical
9
10 422 reasons, which could indirectly affect adherence, especially in patients suffering from statin side effects.

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13 423 *A caregiver (sister) suggested that GPs shouldn't be paid for prescribing statins and that the decision*
14
15 424 *should be based on clinical judgement alone. She suggested medication could be overprescribed as a*
16
17 425 *result for financial reasons [Gender and age unknown, age at stroke unknown, N.78]*

18
19 426
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21
22 427 **Caregivers' difficulties as advocates of patients' medications**

23
24 428 The caregivers' role as advocates for their family members came up in questioning prescribing practices,
25
26 429 highlighting caregivers' awareness of guidelines and difficulties at times with obtaining treatment
27
28 430 modifications on the behalf of patients. (The cost of atorvastatin has dropped since, so this post does not
29
30 431 reflect current practice).

31
32
33 432 *A caregiver recommended being firm with GPs about being put on atorvastatin if simvastatin was not*
34
35 433 *tolerated, as atorvastatin was a bit more expensive but recommended by NICE guidelines as an*
36
37 434 *alternative [Gender and age unknown, age at stroke unknown, N.18].*

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41
42 437 **GPs' role advising about secondary prevention medications**

43
44 438 Some survivors reflected on the role of GPs in their adherence. They felt that the GP's role was to provide
45
46 439 advice. Getting support from family in medication related decisions was considered important.

47
48 440 *A male survivor agreed to stop taking a blood pressure tablet with his doctor because of intolerable*
49
50 441 *side effects, and his wife being a nurse made it easier. He felt strongly that doctors are there to advise*
51
52 442 *not instruct. [Male, age unknown, age at stroke unknown, N.63]*

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444 Caregivers' related views

445 Caregivers also recognized the importance of medications and the need to continue taking tablets despite
446 experiencing side effects. The importance of only stopping medication on GP's advice was highlighted.

447

448 *A caregiver reported that because of side-effects her husband had voluntarily come off all the*
449 *medication he was taking, except for aspirin which he continued to use. She said they had agreed to*
450 *this together with the GP and stressed the importance of doing so before stopping tablets. [Male, age*
451 *54, age at stroke 52, N.68]*

452

453 **Management of medication side effects**

454 **Medications didn't necessarily cause side effects**

455 Survivors who did not experience medication side effects generally felt that taking medication was a positive
456 preventative measure against stroke. Although threads of discussion were not analysed, these posts often were
457 written in reply to users who complained about suffering from side effects.

458 *A male survivor advised it was better taking tablets than risking another mini-stroke. He had a severe*
459 *stroke himself and was prescribed aspirin and simvastatin. He never experienced side effects and also*
460 *knew others on the same statin who didn't experience any either. [Male age 67, age at stroke 63,*
461 *N.52]*

462 **Changing medications to avoid side effects**

463 Forum users reported changes in secondary prevention medications being made by the health professionals to
464 counteract negative side effects, which helped adherence.

465 *A male survivor described that on a dosage of 8mg of warfarin he started to suffer migraines and*
466 *bleeding, leading him to refuse the drug. After further conclusive tests, the consultant decided to take*
467 *him off warfarin as he was taking persantin, which never gave him a headache or nosebleed. He*
468 *acknowledged warfarin was an important drug, but didn't suit everyone. [Male, age 49, age at stroke*
469 *49, N.47]*

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2
3 470 **Perseverance with asking modifications to achieve optimal treatment**

4
5 471 Doctors' and patients' perseverance in modifying medications was important to achieve optimal treatment.

6
7 472 *A male survivor reported taking up to 7 different blood pressure tablets and that it was unusual for a*

8
9 473 *stroke patient to only need a few. He recommended going back to the GP as necessary to keep*

10
11 474 *changing tablets until the right combination was found [Male, age 52, age at stroke 52, N.64]*

12
13 475

14
15 476 Caregivers' related views

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18 477 **Treatment adjustments to avoid side effects**

19
20 478 Reduction of medication dosage by doctors and elimination of side effects was reported as a successful

21
22 479 strategy to aid adherence.

23
24 480 *A female caregiver described her husband suffering from considerable side effects from simvastatin*

25
26 481 *40mg but when the GP changed to atorvastatin at a lower dose of 10mg he was able to cope. [Male,*

27
28 482 *age 54, age at stroke 54, N.49]*

29
30
31 483 **Trusting healthcare professionals**

32
33 484 Healthcare professionals had an important role in patients' trust in secondary prevention medications and

34
35 485 consequently adherence.

36
37
38 486 *A survivor described how he trusted his vascular surgeon who had changed his medication from*

39
40 487 *warfarin to aspirin and statin. The survivor was happy to take aspirin and felt it would be good to*

41
42 488 *continue as the surgeon also took it regularly, concluding it must be beneficial [Survivor, male, age*

43
44 489 *35, age at stroke 34, N.71]*

45
46
47 490

48 491 **Practicalities of secondary prevention medications**

49
50
51 492 **Capability and resources**

52
53
54 493 **Problems associated with taking tablets**

494 **Swallowing and handling medicines**

495 Swallowing difficulties were reported when taking tablets, especially in relation to the medication
496 dipyridamole, due to its size.

497 *A male survivor described 'swallow panic', i.e. fear of choking when trying to take Dipyridamole*
498 *capsules. The user reported it took around 3 months before he got over that. [Male, age 67, age at*
499 *stroke 55, N.70]*

500 Size of tablets also caused handling difficulties due to stroke related impairments.

501 *A survivor agreed with another user about the problem with the size of dipyridamole tablets, which*
502 *were getting stuck in the pill box organizer. [Female, age 46, age at stroke 45, N.30]*

503

504 Caregivers' related views

505 **Treatment burden**

506 Taking multiple tablets also contributed to treatment burden experienced by caregivers. One caregiver
507 described how this added to the survivor's episodic refusal to take any medications.

508 *A caregiver was asking advice on encouraging medication taking. He said his mother was on multiple*
509 *tablets, up to 4 times a day, but was now refusing to take any at all and this did upset him. Persuading*
510 *her to continue taking the most important tablets had taken hours to do. [Male, age 77, age at stroke*
511 *77, N.9]*

512

513 **Attending routine appointments**

514 Another practical difficulty was dealing with routine appointments which were considered burdensome,
515 resulting in the survivors being non-adherent to medications.

516 *A caregiver (wife) described how her husband was adamant that he was not prepared to take statins*
517 *because he didn't have the time to keep going back to the GP for check-ups. The caregiver reported*
518 *feeling helpless. [Male, age 55, age at stroke 55, N.24]*

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3 520 **Difficulties experienced by patients with disabilities**

4
5 521 Caregivers of patients with severe disabilities such as aphasia and inability to communicate, made their job of
6
7 522 ensuring patients' adherence a difficult experience.

8
9
10 523 *A caregiver said she couldn't imagine what a stroke survivor was going through, with her mother*
11 524 *unable to communicate following a stroke. She described her mother having difficulties with*
12 525 *medications caused by previous changes in treatment. She felt her mother was giving up and wanted*
13 526 *advice on dealing with aphasia. [Caregiver-daughter, age 52, age at stroke 47, N.54]*

17 527 **Problems with using storage devices**

18
19
20 528 Using Dosette boxes was sometimes a struggle for survivors with severe disabilities, and a source of worry for
21
22 529 caregivers.

23
24 530 *A caregiver mentioned that despite using a nomad tray, tablets were still being taken from the wrong*
25 531 *day with several days' worth of tablets being taken in a single day. His father in law often didn't take*
26 532 *the time to work out the days or to look at the calendar [Male, age unknown, age at stroke unknown,*
27 533 *N.40]*

32 534 **Seeking advice from pharmacists on managing medications**

33
34
35 535 Another caregiver described having to seek advice on the best way to manage the stroke survivor's
36
37 536 medications.

38
39 537 *A caregiver said he went to the pharmacist and spent half an hour chatting about medications after*
40 538 *which he bought a flip top multi-coloured medication box labeled with the days and doses. He also*
41 539 *said it took him a while to establish the best way to fill the box without getting confused, eventually*
42 540 *filling it a tablet at a time across the entire week, instead of a day at a time. (Male, age 82, age at*
43 541 *stroke 82, N. 57)*

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51 543 **Cost of medication**

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54 544 Survivors' highlighted difficulties faced with meeting the cost of stroke medications.

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2
3 545 *A female survivor described being prescribed both aspirin and simvastatin that she had to pay for.*
4
5 546 *She reported having to take out a credit card to pay for her medications as she was unable to work*
6
7 547 *and did not have any money coming or any benefits. [Female, age 59, age at stroke 59, N.72]*
8
9 548

11 549 **Storage devices and strategies for medication management**

13 550

16 551 **Using medication aids**

17 552 Stroke survivors also reported benefits from using medication aids including pill-boxes and medication
18 553 wallets to facilitate medication taking behavior. These devices ensured the appropriate medication was being
19 554 taken at the right time, while also allowing monitoring when boxes needed to be re-filled.

24 555 *A survivor agreed the storage box was useful to view medication and her husband didn't have to keep*
25 556 *asking her whether she had taken her tablets as he could also see. She said it was irritating to be*
26 557 *constantly asked. The box helped her also with not running out of medications as she filled it weekly*
27 558 *and could tell when it was time for a repeat prescription. [Female, age 46, age at stroke 45, N.30]*
28
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32 559

35 560 Caregivers' related views

37 561 **Using medication instructions**

38 562 Caregivers highlighted how instructions were considered helpful in facilitating day to day medicine taking.
39 563 Keeping track of medicines that had been taken was suggested as a method of ensuring good adherence.

44 564 *A caregiver (son) described making a note on the pill box asking the survivor to turn it over after*
45 565 *taking the pills as this would mean the morning pills were now taken. A second instruction invited the*
46 566 *survivor to do the same when taking the evening tablet. He suggested to forum users that a simple*
47 567 *chart tracking when each medication was taken was also helpful. [Caregiver-son, age 82, age at*
48 568 *stroke 82, N.57]*
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3 570 **Good medication taking routines**

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5 571 **Creating good medication routines**

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7
8 572 Linking daily tablet use to an everyday activity or placing tablets in a specific location which then acted as a
9
10 573 cue to take the medication was described as helpful by several users.

11
12 574 *A survivor suggested using a white board and having method in place helped. She remembered taking*
13
14 575 *her own medications through repetition or linking tablet use to another everyday activity [Female,*
15
16 576 *age 54, age at stroke 46, N.19]*

17
18
19 577

20
21 578 Caregivers' related views

22
23
24 579 **Reminding survivors about taking tablets**

25
26
27 580 Caregivers also played a key role in medication routines when survivors couldn't remember to take tablets.

28
29 581 *A caregiver (wife) described regularly giving her husband his medication because stroke had caused*
30
31 582 *short term memory loss and he would forget them or sometimes take them over again. She said she*
32
33 583 *was now in total control of his medications which was fine because she was a nurse with experience*
34
35 584 *of this. [Female, Age 46, age at stroke 40, N.5]*

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40 586 **DISCUSSION**

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43 587 **Summary of main findings**

44
45 588 Data from an online forum provided a rich source of information, illuminating on practical and perceptual
46
47 589 barriers and facilitators to adherence to secondary prevention medications in stroke survivors and their
48
49 590 caregivers. These data highlight several points. Concerns around the bad press on statins could result in stroke
50
51 591 survivors being cautious about commencing/keep taking the medication, and opting for a change in diet as an
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53 592 alternative (potentially a not medically appropriate decision and without healthcare professionals' support).
54
55 593 Survivors expressed concerns about being prescribed medications they considered inappropriate, questioned
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3 594 GPs' motivation to prescribe medications and at times realised when prescribing mistakes occurred.
4
5 595 Caregivers themselves reported some doubts about the effectiveness of tablets and difficulties in ensuring
6
7 596 good medication adherence, while recognising that it is ultimately a survivor's decision whether or not to take
8
9 597 medication, particularly when suffering from side effects. Indeed, not experiencing side effects from
10
11 598 secondary prevention medications was an important facilitator of adherence. Health professionals successfully
12
13 599 modifying treatment to manage side effects and awareness that not everyone suffers from side effects were
14
15 600 reported as increasing the motivation to take secondary prevention treatment. Believing that medications
16
17 601 reduced stroke risk, feeling reassured by taking secondary prevention treatment and experiencing another
18
19 602 cerebrovascular event as consequence of nonadherence were important drivers of necessity beliefs and
20
21 603 supported adherence.

22
23
24 604 Practical barriers included difficulties swallowing capsules, burden of multiple medications, stroke-related
25
26 605 communication impairments (e.g. aphasia) causing patients' confusion with any treatment changes,
27
28 606 difficulties meeting medication costs and with managing storage devices. Caregivers' posts greatly
29
30 607 contributed to these data. They reported that improved patients' adherence was linked to using medications
31
32 608 storage devices, getting help from pharmacists in organising medicines, assuming full control of their family
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34 609 members' medication taking, and having previous experience and knowledge about medications and their
35
36 610 administration.

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40 41 612 **Strengths and limitations**

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43
44 613 This study has a number of strengths. Firstly, the method of data collection where descriptions by forum users
45
46 614 capture unprompted thoughts is unlikely to be affected by self-presentational bias. Information comes from
47
48 615 patients over a wide geographical area and includes people who might not take part in traditional research
49
50 616 because of severe disabilities, communication impairments or in the case of caregivers, because of lack of
51
52 617 time.¹¹ The forum creates a natural environment facilitating exchange in opinions and in-depth discussions
53
54 618 around several topics including secondary prevention medications. The important presence of caregivers in
55
56 619 online discussions is a further strength, offering a unique viewpoint on medication taking behavior of

1
2
3 620 survivors with severe disabilities. Given that patients with significant disabilities may not traditionally
4
5 621 participate in health research, the online forum may represent a potentially important method of data
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7 622 collection through which these patients' views may be heard through their caregivers.
8
9

10 623 These findings however should be interpreted with caution. A key limitation of this research was that
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12 624 forum data was from the years 2004- 2011 and therefore the findings reported here may not reflect current
13
14 625 practice in primary care. Lack of details about the underlying clinical scenarios described in some of the posts
15
16 626 made it difficult classifying emerging themes as barriers or facilitators to adherence. In addition, barriers and
17
18 627 facilitators were limited to those identified from the pre-defined search criteria. Different keywords may have
19
20 628 uncovered additional barriers to medication adherence we failed to identify, or revealed issues related to
21
22 629 medications in general rather than specifically secondary prevention ones. All forum posts were examined by
23
24 630 a moderator prior to being published online which may have restricted the views of some users. Finally, with
25
26 631 the majority of forum users under the age of 70, it is possible that this method of data collection overlooks a
27
28 632 significant proportion of the older stroke population.
29
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31 633

32 33 634 **Comparisons with existing literature**

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35
36 635 Our investigation shed light on the significance stroke survivors and caregivers attributed to the bad
37
38 636 press on statins, which impacted on their adherence. This is in agreement with a recent investigation
39
40 637 concluding that negative statin related news stories was associated with early discontinuation of statin and
41
42 638 increased risk of death by cardiovascular disease.²⁶ Furthermore, people already taking statin were found to
43
44 639 be more likely to stop this medication following high media coverage,²⁷ or when side effects were not
45
46 640 tolerable despite GP's attempts to modify treatment.¹⁷ Beliefs about secondary prevention medications
47
48 641 differed at times between survivors and caregivers. Some stroke survivors decided to stop medications
49
50 642 because of intolerable side effects, despite their caregivers' believing optimal adherence was important to
51
52 643 prevent stroke recurrences. In the context of medication side effects, caregivers believed in their role as
53
54 644 patients' advocates with healthcare professionals (including GPs and pharmacist) and often discussed and
55
56 645 sought advice from other users in the forum on the matter. Findings from the present study also highlight the
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2
3 646 difficulties experienced by stroke survivors using blister packaged medication and dosette boxes, despite at
4
5 647 the same time outlining their benefit in terms of adherence. Evidence from a systematic review has
6
7 648 demonstrated significant improvement in adherence for those in the group using reminder packaging²⁸ as
8
9 649 well as using pill boxes and blister packs in packaging interventions in cardiovascular disease²⁹ while the use
10
11 650 of reminder packaging may be a simple way of improving adherence to medication³⁰ With older people
12
13 651 known to experience difficulties taking medication, developing interventions that seek to combine the use of
14
15 652 medication management devices with caregiver co-operation may be one way of addressing the practical
16
17 653 challenges they face.

18
19
20 654 This study highlights a couple of interesting findings. Survivors reported making decisions about
21
22 655 taking or not secondary prevention medications sometimes independently from their GPs, despite considering
23
24 656 GPs' support important. Collaborative decision making involving caregivers, clinicians or pharmacists may
25
26 657 however empower stroke survivors to make better informed decisions about secondary prevention
27
28 658 medications. Understanding how patients make decision about medications is important³¹ and GPs may
29
30 659 benefit from enhancing caregivers' role in the decision making process about medications.

31
32
33 660 Barriers to caring for the stroke survivor post hospital discharge have included a lack of collaboration with the
34
35 661 healthcare team and a lack of community support for the caregiving role³² as well as insufficient knowledge
36
37 662 and skills to care for the survivor in the home.³³ We described in this study the struggle caregivers face in their
38
39 663 role as advocate of patients, on one side engaging with healthcare professionals for ensuring that
40
41 664 recommended secondary prevention treatment is received, and on the other side wanting to support and
42
43 665 respect patients' decisions about taking or not taking medications. Caregivers facing this dilemma could
44
45 666 benefit from greater support by GPs and pharmacists. Caregivers could play an important role in bridging the
46
47 667 gap between health professional and stroke survivor in primary care and deserve more research and clinical
48
49 668 attention. Developing interventions that seek to encourage active caregivers' engagement in stroke survivors'
50
51 669 and healthcare professionals' shared-decision making, can help to address more comprehensively barriers to
52
53 670 adherence as well as delivering a care program tailored to the individual needs of patients.⁸

1
2
3 671 Barriers highlighted here are in line with those reported by another qualitative study, where negative
4
5 672 or erroneous beliefs about tablets, doubts around the effectiveness of medication and concerns about the
6
7 673 consequences of not taking tablets were associated with being low adherers.³⁴ Greater emphasis on informing
8
9 674 stroke survivors and caregivers about secondary prevention medications in primary care is needed. In a recent
10
11 675 randomised trial evaluating an educational package for stroke survivors and caregivers, participants who
12
13 676 received tailored information along with verbal reinforcement reported a greater satisfaction with medical and
14
15 677 practical services.³⁵
16
17
18 678 Survivors' concerns around the need for secondary prevention medications may reflect a wider pattern of
19
20 679 misunderstanding about the benefits of such drugs. In an assessment of attitudes towards taking cardiovascular
21
22 680 medications, caution expressed around medications was linked with how great their risk to health was
23
24 681 perceived to be.³⁶ A meta-analysis examining the necessity-concerns framework across a range of conditions
25
26 682 found that experiencing the consequences of nonadherence reinforced the subsequent need to take tablets,
27
28 683 acting as a driver of medication adherence,³⁷ in agreement with what is reported in this study by both stroke
29
30 684 survivors and caregivers.

31
32
33 685

34
35 686 Although statins are known to reduce the risk of stroke by as much as 25%,³⁸ benefits are undermined
36
37 687 by suboptimal adherence. In a previous examination on patient perspectives around statin therapy,
38
39 688 compliance with statins was associated with information provided during the practitioner consultation as well
40
41 689 as the beliefs about cholesterol and current health status³⁹. This concurs with the findings in our study. In a
42
43 690 recent investigation exploring nonadherence and patient's perceptions towards statins, it was found that up to
44
45 691 three quarters of participants doubted the necessity of statins, lacked knowledge about this medication, and
46
47 692 concerns around side effects were significantly associated with intentional nonadherence.⁴⁰

48
49
50 693 In this online forum we found evidence that stroke survivors establish routines and use cues to facilitate
51
52 694 medication taking. This is in agreement with previous findings, including a pilot trial in which a plan to
53
54 695 establish medication routine resulted in significantly greater adherence among survivors.^{41,42} Providing
55
56 696 support to establish medication taking routines particularly among older patients with stroke can be

1
2
3 697 beneficial.⁴³ Challenges to adherence with warfarin therapy, including beliefs about the need for this treatment
4
5 698 have been highlighted previously, suggesting the benefit of a more collaborative patient - practitioner
6
7 699 approach, focusing on education around anticoagulant therapy.⁴⁴
8

9
10 700 These findings add to current literature by providing an assessment of adherence from users of an
11
12 701 online forum. There has been little research on this approach to data collection conducted to date. The study
13
14 702 identifies adherence concerns of a younger stroke population who may be less likely to be represented in
15
16 703 research studies and whose attitudes to medication may be less well known. Findings add to the literature and
17
18 704 shed lights on dynamic interactions between the survivor, caregiver and health professionals and the extent to
19
20 705 which this influences medication adherence in this patient group.
21

22 706

23 707

24 708 **Implications for clinical practice**

25 709 These findings demonstrate the need to address identified barriers to adherence to secondary prevention
26
27 710 medications within clinical practice. Improving patient- and caregiver-practitioner communication through
28
29 711 more effective clinical consultations has the potential to benefit patients and encourage a greater
30
31 712 understanding of the importance of secondary prevention medications. This approach could contribute not
32
33 713 only to shaping patients' beliefs about medications but also to improving confidence around taking them.
34
35 714 Challenging negative medication beliefs and adopting practices that implement simple medication taking
36
37 715 routines and appropriate use of tablet storage devices, particularly for those patients with more severe
38
39 716 disabilities as a result of stroke, can increase adherence and ultimately improve health outcomes.^{40, 41}
40

41 717 Both primary and secondary healthcare professionals should seek to engage the family of survivors and their
42
43 718 support network to challenge concerns around taking tablets, offer reassurance on the benefits of medications,
44
45 719 discuss the need for treatment in light of side effects, and even support patients' informed decision to refuse
46
47 720 medications.
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3 721 Interventions using ‘expert patients’ or ‘expert caregivers’ providing support to stroke survivors and
4
5 722 caregivers in the primary care setting hold potential.¹⁵
6
7 723 Internet fora for patients with stroke provide a potentially important resource through which the attitudes of
8
9 724 survivors and their caregivers towards medication use can be better understood.
10
11 725 These findings provide new insight to clinicians about younger stroke survivors’ concerns and the struggles
12
13 726 caregivers might face in their role as patients’ advocates. Awareness of these factors will improve
14
15 727 consultations about secondary prevention medication with both younger survivors and stroke survivors’
16
17 728 caregivers. Stroke survivors with severe disabilities and their caregivers experience significant practical
18
19 729 barriers to adherence. Greater focus on such practicalities by healthcare professionals would be beneficial.
20
21 730 This study highlights caregivers’ unique position in overseeing patients’ medications. Exploring the stroke
22
23 731 survivor-caregiver dynamic can shed light on potential barriers to adherence to secondary prevention
24
25 732 medication and ways to address them, eventually improving patients’ outcomes.
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733

734 **Future research**

735 Our study suggests that caregivers play an important role in bridging the gap between patient and practitioner
736 with regard to informing and facilitating the medication taking process. Future research should therefore
737 further explore their role in stroke survivors’ medication taking and systematically incorporate them into
738 adherence interventions.

739 Given the strong focus of forum users on statins, understanding why stroke survivors choose not to take
740 statins as prescribed and suggesting to healthcare professionals effective ways of dealing with this issue
741 should be a key focus for research in this area. With adverse events the most common reason for poor
742 adherence to statin therapy, improved patient understanding of this medication through greater
743 communication with the practitioner can help to address ongoing concerns.⁴⁵

744 Future interventions should aim at further improving medication taking routines after stroke, using cues to
745 prompt tablet taking. Advances in technology could facilitate delivery of such interventions. One novel
746 approach to improving adherence particularly with regards to multiple medications is the use of fixed-dose

1
2
3 747 combination therapy ‘polypill approach’.⁴⁶ Indeed a recent systematic review of barriers and facilitators of
4
5 748 adherence to secondary prevention medications within cardiovascular disease found fixed dose combination
6
7 749 (FDC) therapy to be an important facilitator associated with high adherence.⁴¹
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10 750

11 751 **Conclusion**

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15 752 This study identified barriers and facilitators to medication adherence for stroke through analysing data from
16
17 753 an online forum using a framework approach. Developing interventions which build on these results according
18
19 754 to the framework has the potential to improve medication adherence and ultimately reduce the burden of
20
21 755 stroke. Greater efforts are needed to meet the growing challenges faced by stroke survivors and their
22
23 756 caregivers and to enable primary care clinicians to effectively address the burden of nonadherence to
24
25 757 secondary prevention medications.
26

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28
29
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31
32 760 forum.
33

34 761 Competing Interests

35
36
37 762 None declared
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39 763 Author/s contribution

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42
43 764 ADS conceived of the study, is the Chief Investigator, contributed to the data analysis and commented on the
44
45 765 manuscript. JM is a co-investigator on the study, wrote and commented on the manuscript. SS is a co-
46
47 766 investigator on the study, wrote and commented on the manuscript. JJ contributed to the study design,
48
49 767 conducted the data analysis and prepared the manuscript for submission. All authors agreed on the final draft
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51 768 of the submitted manuscript.
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	N	Median Range	
Sample characteristics			877
Total participants identified in posts	84		878
Number of posts in the forum/ participant		16 (1-4932)	879
Number of posts about secondary prevention medications/ participant		1 (1-37)	880
Age at stroke			881
Survivor		50 (32-72)	882
Patient by caregiver		66 (46-91)	883
Gender			884
Male -Survivor	20		885
Female- Survivor	26		886
Not known - Survivor	3		887
Male -Patient talked about by caregiver	20		888
Female - Patient by caregiver*	12		889
Unknown gender and unknown identity	3		890
Identity person posting			891
Stroke survivor	49		892
Caregiver	33		893
Not known	2		894
Years since stroke			895
(0-12 mths)	37		896
(1-5 yrs)	25		897
(6-10 yrs)	4		898
(11-15 yrs)	2		899
(15+ yrs)	1		900
Unknown	15		901
Caregiver identity			902
Daughter /son	20		903
Spouse	9		904
Other (/in law/ sister)	3		905
Unknown	1		906
Legend: * Patient talked about by a caregiver			907

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Table 1. Characteristics of online Talkstroke participants as identified in the study posts

Perceptions	
Barriers	Facilitators
<p>Necessity beliefs Lack of perceived benefits of medication</p> <ul style="list-style-type: none"> • Questioning the effectiveness of secondary prevention medications in preventing stroke recurrence. • Considering statins detrimental to health and not effective. • <i>Valuing adherence but recognising that is the choice of the patient to take tablets.</i> • <i>Realising that stroke could still occur despite taking secondary prevention medications.</i> <p>Concerns Management of medication side effects*</p> <ul style="list-style-type: none"> • Experiencing statins side effects and considering they have potential to worsen quality of life. • Changing diet/lifestyle as alternative to taking medication to reduce side effects.* • Healthcare professionals recommending diet and exercise to reduce cholesterol instead of taking statins.* • <i>Struggling to raise issues about side effects of statins with healthcare professionals and obtaining changes in treatment when patients find it unsuitable.</i> <p>Impact of bad press on statins</p> <ul style="list-style-type: none"> • Being extra-cautious about commencing 	<p>Necessity beliefs Attributing importance to medications</p> <ul style="list-style-type: none"> • Recognising taking tablets as important to prevent stroke recurrence. • Feeling reassured by taking secondary prevention medications. • Experiencing consequences of nonadherence (a further stroke) as driver of necessity beliefs. • <i>Feeling secondary prevention medications are important and should only be stopped in consultation with the GP.</i> • <i>Holding strong beliefs about the need for secondary prevention medications.</i> <p>Concerns Management of medication side effects*</p> <ul style="list-style-type: none"> • Awareness that not all patients are affected by side effects. • Healthcare professionals changing medications to counteract side effects • Modifying medications to achieve optimal treatment • <i>Obtaining changes in treatment from healthcare professionals until side effects are manageable</i> <p>Trusting healthcare professionals</p> <ul style="list-style-type: none"> • Perceiving medications to be beneficial as secondary healthcare

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<p>statins for fear of side effects</p> <ul style="list-style-type: none"> • <i>Struggling to ensure patients' adherence to statins in face of bad press.</i> <p>Questioning prescribing practices</p> <ul style="list-style-type: none"> • Being disappointed as medications considered ineffective were not changed by GPs. • Having concerns around incorrect medications being prescribed. • Receiving conflicting information about medications. • <i>Worrying about medications being prescribed for financial reasons or guidelines over clinical judgement</i> • <i>Experiencing difficulties with asking GPs to prescribe alternative tablets as current ones considered unsuitable.</i> • <i>Feeling the role of GPs is limited to advising about secondary prevention medications</i> • <i>Intentionally missing medications to manage side effects</i> 	<p>professional also taking it.</p>
Practicalities	
Barriers	Practicalities
<p>Problems associated with taking tablets</p> <ul style="list-style-type: none"> • Swallowing medication capsules, especially big size ones. • Experiencing difficulties with handling medications due to size and stroke related physical impairments. • <i>Experiencing frustration with burden of multiple medications and episodic patients' refusal of medications.</i> • <i>Experiencing frustration at patient refusal to take statins and attend routine medication appointment.</i> • <i>Experiencing difficulties when helping patients with aphasia taking tablets in the context of changes in treatment.</i> • <i>Experiencing frustration at patients failing to keep up with refilling prescriptions.</i> <p>Cost of medications</p> <ul style="list-style-type: none"> • Struggling to meet the costs of secondary prevention medications. 	<p>Storage devices for managing medication</p> <ul style="list-style-type: none"> • Using pill box: helping seeing the correct medication was taken and when prescription needed to be renewed. • <i>Using pill-boxes to provide written instruction to patients or keeping a note of tablets taken.</i> • <i>Advice from pharmacist on taking medication correctly.</i> <p>Good medication taking routines</p> <ul style="list-style-type: none"> • Linking tablet use to an everyday activity to facilitate medication taking behaviour. • <i>Assuming control of medication</i>

	<i>when patients have problems with short term memory and reminding when tablets have to be taken.</i>
<p>Legend: Statements in italics refer to caregivers' themes. * Because of missing details of the underlying clinical scenario, these themes could act both as barriers or facilitators to adherence to secondary prevention medications, therefore have been reported under both headings.</p>	

911 Table 2. Key themes highlighting survivors' and caregivers' barriers and facilitators to adherence to
912 secondary prevention medications classified according to perceptions and practicalities.

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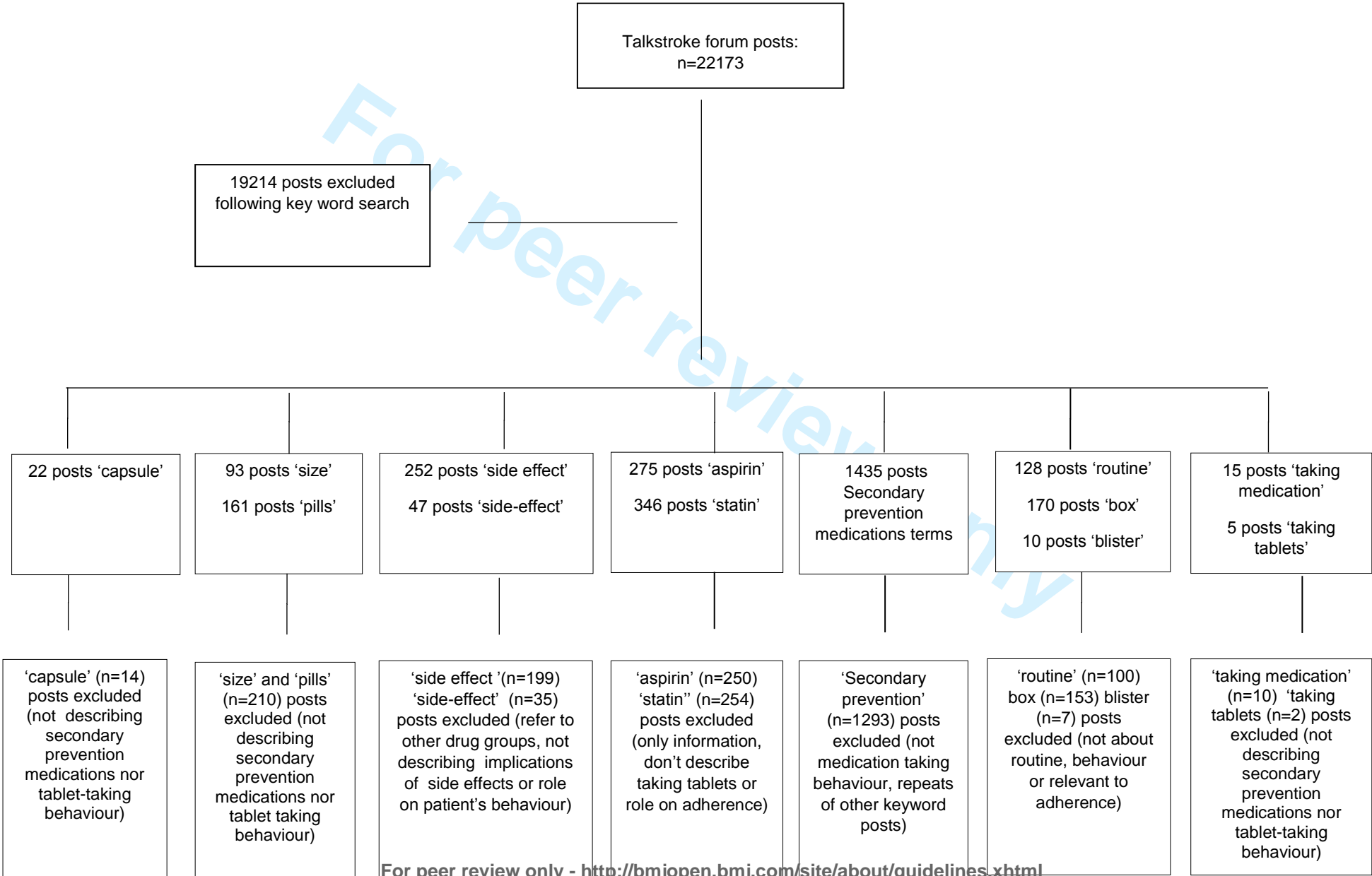
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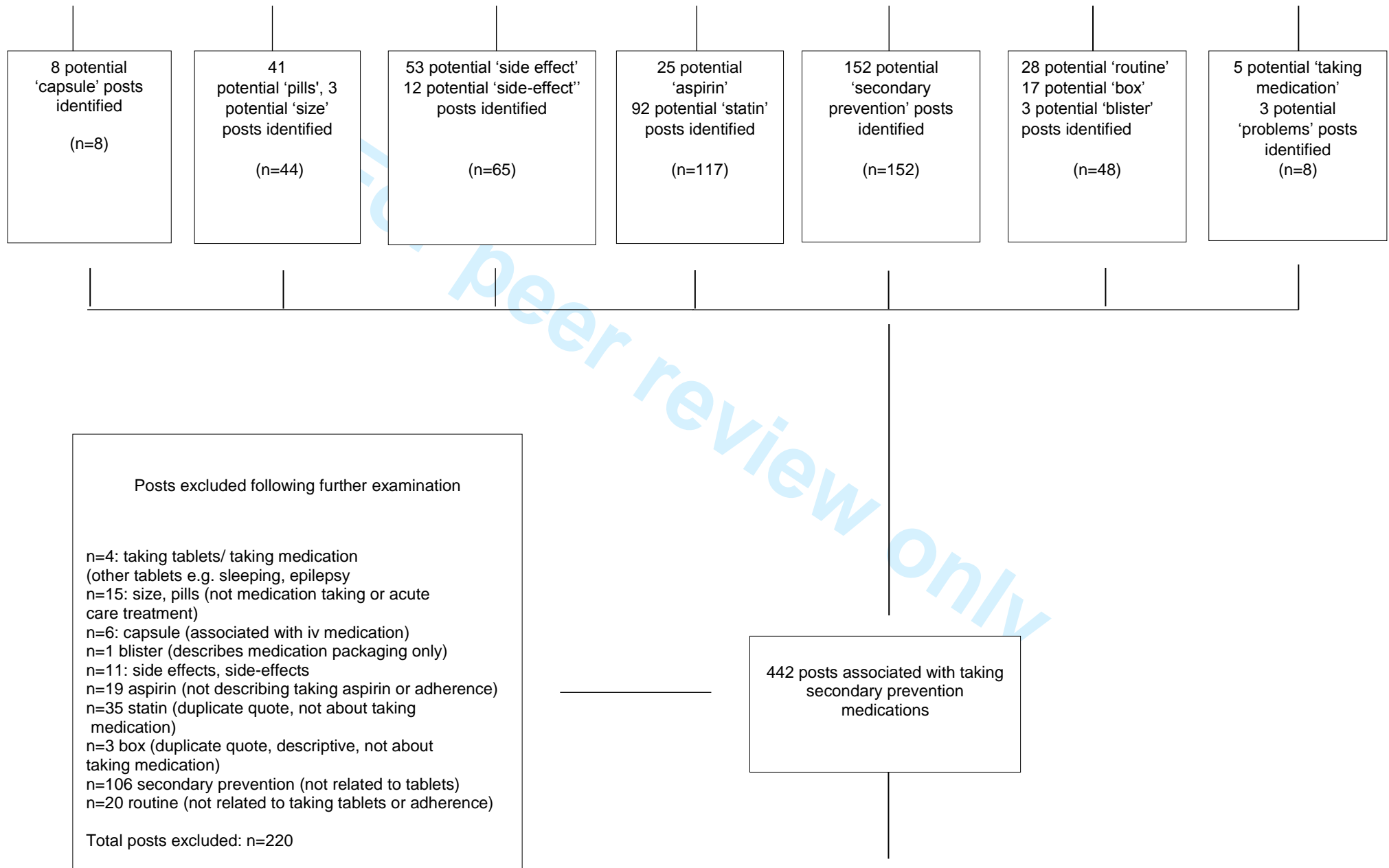
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Supplementary File 1. Analysis strategy to identify study posts

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Posts analysed: thematic analysis on themes classified as barriers or facilitators of medication adherence.

n= 4: Taking medication/ taking tablets
n= 29: Size, pills
n= 2: Capsule
n= 2: Blister
n= 54: Side effects, side-effects
n= 14: Box
n=109: Secondary prevention medication terms
n= 8: routine

Total posts included: n= 222

Thematic analysis: Development of themes associated with barriers and facilitators of medication adherence

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Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description	
Domain 1: Research team and reflexivity			
Personal Characteristics			
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	N/A
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	BSc, MSc
3.	Occupation	What was their occupation at the time of the study?	Research Assistant/ PhD Student
4.	Gender	Was the researcher male or female?	Male
5.	Experience and training	What experience or training did the researcher have?	JJ is a researcher with experience in undertaking qualitative research.
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	N/A
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	N/A
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	N/A
Domain 2: study design			
Theoretical framework			
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis,</i>	Thematic analysis: Pg. 7

No	Item	Guide questions/description	
		<i>ethnography, phenomenology, content analysis</i>	
	Participant selection		
10.	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>	All users of an online forum who posted comments on medication adherence were eligible for inclusion Pg. 6
11.	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>	Participants were not directly approached. Information they submitted to an online forum was analysed Pg. 6
12.	Sample size	How many participants were in the study?	84 Pg. 8
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	N/A
	Setting		
14.	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	Data was collected from an online forum electronically and remotely. Pg. 6
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	N/A
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	Gender, age, stroke survivor/ caregiver, years since stroke occurred Pg. 8
	Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	N/A
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	N/A
19.	Audio/visual recording	Did the research use audio or visual recording to	N/A

No	Item	Guide questions/description	
		collect the data?	
20.	Field notes	Were field notes made during and/or after the interview or focus group?	N/A
21.	Duration	What was the duration of the interviews or focus group?	N/A
22.	Data saturation	Was data saturation discussed?	Yes Pg. 7
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No
Domain 3: analysis and findings			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	2 authors contributed to the coding process. JJ coded all of the forum posts. 20% of posts were independently coded by ADS. Pg. 7
25.	Description of the coding tree	Did authors provide a description of the coding tree?	Table 2 reports all the themes that were identified and coded from the data. Pg. 33
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Themes were generated from the data Pg. 9-21, 33
27.	Software	What software, if applicable, was used to manage the data?	Microsoft Excel, Nvivo qualitative analysis software Pg. 6
28.	Participant checking	Did participants provide feedback on the findings?	No
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>	Yes, however, for ethical reasons and to protect participant confidentiality quotes were presented as descriptions, rather

No	Item	Guide questions/description	
			than quotes literally extracted from the online forum. Participants were only identified by a unique number. Pg. 6
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes Pg. 7-21
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes Pg. 7-21
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes. Key themes and sub-themes are reported. Restrictions on word count prevented themes being discussed extensively Pg. 7-21