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Qualitative Research

How do stroke survivors and their carers use practitioners' advice on secondary prevention medications? Qualitative study of an online forum

Nkeonye J Izuka[a], Matthew A W Alexander[b], Chantal Balasooriya-Smeekens[b], Jonathan Mant[b] and Anna De Simoni[a,*]

[a]Centre for Primary Care and Public Health, Barts and The London School of Medicine and Dentistry, Yvonne Carter Building, QMUL, London E1 2AB, UK, [b]Primary Care Unit, Department of Public Health, University of Cambridge School of Clinical Medicine, Cambridge CB1 8RN, UK.

*Correspondence to Anna De Simoni, Centre for Primary Care and Public Health, Barts and The London School of Medicine and Dentistry, Yvonne Carter Building, QMUL, London, E1 2AB, UK; E-mail a.desimoni@qmul.ac.uk

Abstract

Background. Secondary prevention medications reduce risk of stroke recurrence, yet many people do not receive recommended treatment, nor take medications optimally.
Objective. Exploring how patients report making use of practitioners' advice on secondary prevention medicines on an online forum and what feedback was received from other participants.
Methods. Thematic analysis of the archive of Talkstroke (2004–2011), UK. Posts including any secondary prevention medication terms, General Practitioner (GP) and their replies were identified.
Results. Fifity participants talked about practitioners' advice on secondary prevention medications in 43 discussion threads. Patients consulted practitioners for reassurance and dealing with side effects. Practitioners' advice varied from altering to maintaining current treatment. Three main themes emerged from the use of practitioners' advice: patients following advice (reassured, happy when side effects made tolerable, or still retaining anxiety about treatment); patients not following advice (admitting adherence on-off or stopping medications as side effects still not tolerable); asking other participants for feedback on advice received. Practitioners' advice was disregarded mainly when related to dealing with statin side effects, after one or two consultations. Themes for feedback involved sharing experience, directing back to practitioners, or to external evidence.
Conclusions. Side effects of secondary prevention medications and statins in particular, cause anxiety and resentment in some patients, and their concerns are not always addressed by practitioners. Practitioners could consider more proactive strategies to manage such side effects. Forum feedback was appropriate and supportive of the practitioners' advice received. Our findings from peer-to-peer online conversations confirm and widen previous research.

Key words: General Practitioners, internet, medication adherence, primary health care, stroke, secondary prevention.

Introduction

Three in 10 stroke survivors will go on to have a recurrent stroke or TIA, which are potentially preventable (1). The estimated cost of stroke care in UK is about £9 billion a year (1,2). The use of antihypertensives, lipid lowering agents and anticoagulants/antiplatelets may reduce the risk of stroke by about 75% (3). However, persistence with secondary prevention medications decreases over time, in particular for statins and anticoagulants/antiplatelets (4). Data from the Netherlands revealed that by 1 year after stroke, 22% of stroke survivors who had been taking oral anticoagulation had stopped, half of whom did so 'for non-medical reasons' (5).

Additionally, suboptimal adherence in stroke survivors still on secondary prevention medications treatment also leads to inadequate risk factor control (6,7). Patients' perceptions of their medicines influence medicine-taking behaviour: absence of concerns about medications, knowledge of side effects, clear understanding of the consequences of non-adherence and a good routine of taking medications have been identified as factors associated with better adherence after stroke (8–10).

Primary care practitioners play a pivotal role in managing secondary prevention medications in stroke survivors. Although the quality of prescribing in the secondary prevention of stroke is reported to be good (11,12) evidence shows that many of the difficulties stroke survivors have adhering to secondary prevention strategies are potentially preventable with tailored information, monitoring and follow-up by primary healthcare professionals (13). Appropriate interaction between patient and health professional is recognized as becoming an increasingly important factor (14) and its quality correlating with the success of self-management, adherence, satisfaction and health outcomes (15,16).

Online fora allow social interactions, through which participants can join in the discussions at their own convenience. Stroke survivors of both sexes, across a wide age range and disability degrees accessed the online forum of the Stroke Association (17). There is evidence that inappropriate medical information or health behaviours can be identified and corrected by peers in stroke (17) and cancer fora (18).

The aim of this study was to identify whether practitioners' advice on secondary prevention medications was discussed within the forum and analyse how stroke survivors and their carers used such advice, to inform interactions between patients and primary care health professionals in the context of secondary prevention medications.

Methods

Design

We conducted a qualitative analysis of stroke survivors' posts on a moderated UK web forum. We included posts about practitioners' advice on secondary prevention medications written by stroke survivors and by people posting about stroke survivors.

Setting

The analysis was performed on the archives from TalkStroke, a UK based online forum hosted by the Stroke Association website, with 21 596 posts written between 2004 and 2011 by 2,348 participants (17).

Ethics

The Stroke Association transferred the archives to ADS with permission to use the data for research purposes. More extensive details about the ethics of performing research on this online forum are reported elsewhere (17). To protect the identity and intellectual property of forum participants, we chose not to use quotes, despite this being normal practice in qualitative research. Instead, we used descriptions of quotes throughout the text. We did not apply our own interpretation to these descriptions, but aimed to summarise what was being said.

Identification of study participants

A word list of unique terms of the archive file of Talkstroke was generated using AntConc3.2.4 (19), an online free corpus analysis toolkit for text analysis. Terms related to secondary prevention medications were selected (e.g. Amlodipine, statin, warfarin), including misspellings (e.g. Asprin, simvastin), brand names (e.g. Lipitor, Plavix) and drug categories (e.g. statin, diuretics etc.). Posts including both secondary prevention medications terms and [i.e. General Practitioner 'GP'] were identified (see Figure 1). Participants were identified by the usernames linked to selected posts. Characteristics of stroke survivors including demographics and information of

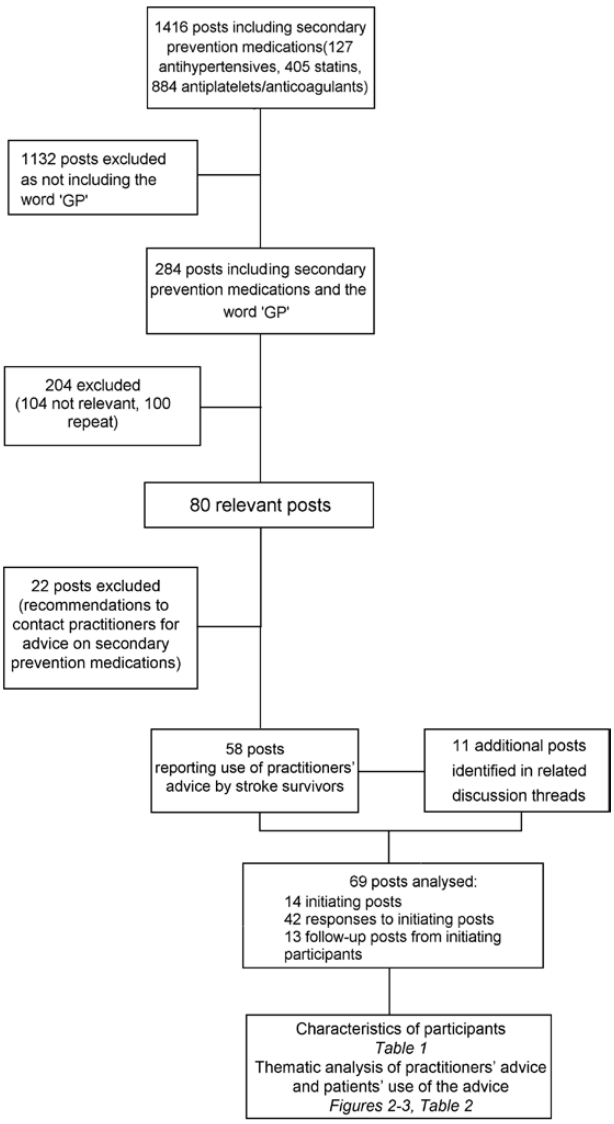

Figure 1. Flowchart illustrating the analysis.

stroke type (see Table 1) were retrieved from the usernames taking advantage of data from a previous study (17).

The threads of discussions for each selected post were analysed in details. Posts located chronologically before or after the selected posts were added to the analysis, provided they were discussing the use of practitioners' advice on secondary prevention medications. These extra posts did not necessarily include the word 'GP' and secondary prevention medications terms.

Table 1. Characteristics of study participants

Dataset Archives of the Talkstroke forum 2004 to 2011, 2348 participants, UK Sample characteristics	*N*	Median (range)
Total number of participants in this study	50	
Age at stroke	37	49 years (17–88)
Participants' posts		
Number of posts on the forum/participant		16 (1–4932)
Number of posts about use of practitioners' advice on secondary prevention medications/participant		1 (1–13)
Identity person posting		
Stroke survivor	33	
Carer	17	
Gender of stroke survivor		
Male	21	
Female	27	
Not stated	2	
Type of stroke		
Ischemic	6	
Haemorrhagic	4	
Stroke (unspecified)	35	
TIA	5	
Secondary prevention medication class[a]	No of posts	
Antihypertensives	17	
Statins	33	
Antiplatelets/anticoagulation	37	

[a]Each post may include discussion about one or more medication classes.

Analysis

Posts were analysed using thematic analysis using an inductive or bottom up approach (20,21). An initial coding framework was developed, which was adjusted as new data were added. Coding was performed independently by Nkeonye J Izuka and Anna De Simoni. Analysis was discussed until agreement was reached and the coding framework finalised.

The feedback received by the forum was performed by Matthew A W Alexander and ADS. Posts were defined as 'false' when including factually incorrect statements and 'misleading' when likely leading a medically naive reader to a false factual conclusion, according to what reported by Esquivel et al in a study on online peer support group for cancer (18).

Cytoscape software (22) (an open source software platform for visualizing complex system analysis) was used to create the association graph grouping the emerging themes (Figures 2 and 3).

Results

The archives contained 1416 posts naming secondary prevention medication terms (see Figure 1). Posts selected were part of 43 different discussion threads. Analysis of threads brought additional 11 posts to the analysis, up to a total of 69 posts: 14 posts initiating the conversation about the use of practitioners' advice on secondary prevention medications, 42 responses to initiating posts, 13 returning posts written by the same participants who started the conversation.

Participants

A total number of 50 participants posted about use of practitioners' advice on secondary prevention medications, 33 stroke survivors and 17 carers (see Table 1). There were 27 females, 21 males and 2 participants whose sex was not stated. The median age of participants was 49 years. The average period since stroke was 2.3 years, while the median 0 years, indicating that at least half of participants took part in the forum within a year since suffering from stroke.

Themes

Initial coding revealed four over-reaching categories, under which themes were grouped: (i) patients' main issues for asking practitioners' advice, (ii) practitioners' advice received on secondary prevention medications, (iii) patients' use of practitioners' advice and (iv) feedback received by other forum participants.

The thematic analysis is summarised in Figures 2 and 3.

Patients' main issues for asking practitioners' advice

Patients' reasons for consulting their practitioners fell into two main categories (see Figure 2 and 3).

1) Being on correct treatment. Patients consulted their practitioner to reassure themselves they were on the correct secondary prevention medications.

A woman had lost use of her right arm, leg and speech. She was commenced on warfarin for life due to her atrial fibrillation. Her GP had reassured her that as long as she was on warfarin, the risk of getting another stroke was low. (Female, age and age of stroke not stated, N13).

2) Dealing with side effects.

A woman asked her GP if she could stop taking the statins due to the horrible head pain that was supposed to only last short term but seemed to continue every day. (Female, current age and age at stroke not stated, N3).

Practitioners' advice on secondary prevention medications

Four main themes emerged on the type of practitioners' advice reported by forum participants (see Figures 2 and 3).

1) Changes to medications: starting/stopping or modifying secondary prevention medications.

A man was on antihypertensives, anticoagulants and simvastatin simultaneously. He developed painful muscular spasms/cramps and his GP decided to try discontinuing the simvastatin to see whether responsible for his symptoms. (Male, present age and age at stroke not stated, N8).

A woman described her GP placing her on atorvastatin 10 mg and increasing it slowly to avoid side effects. She was tolerating this well. (Female, age and age at stroke 54 years, N22).

2) No change in treatment.

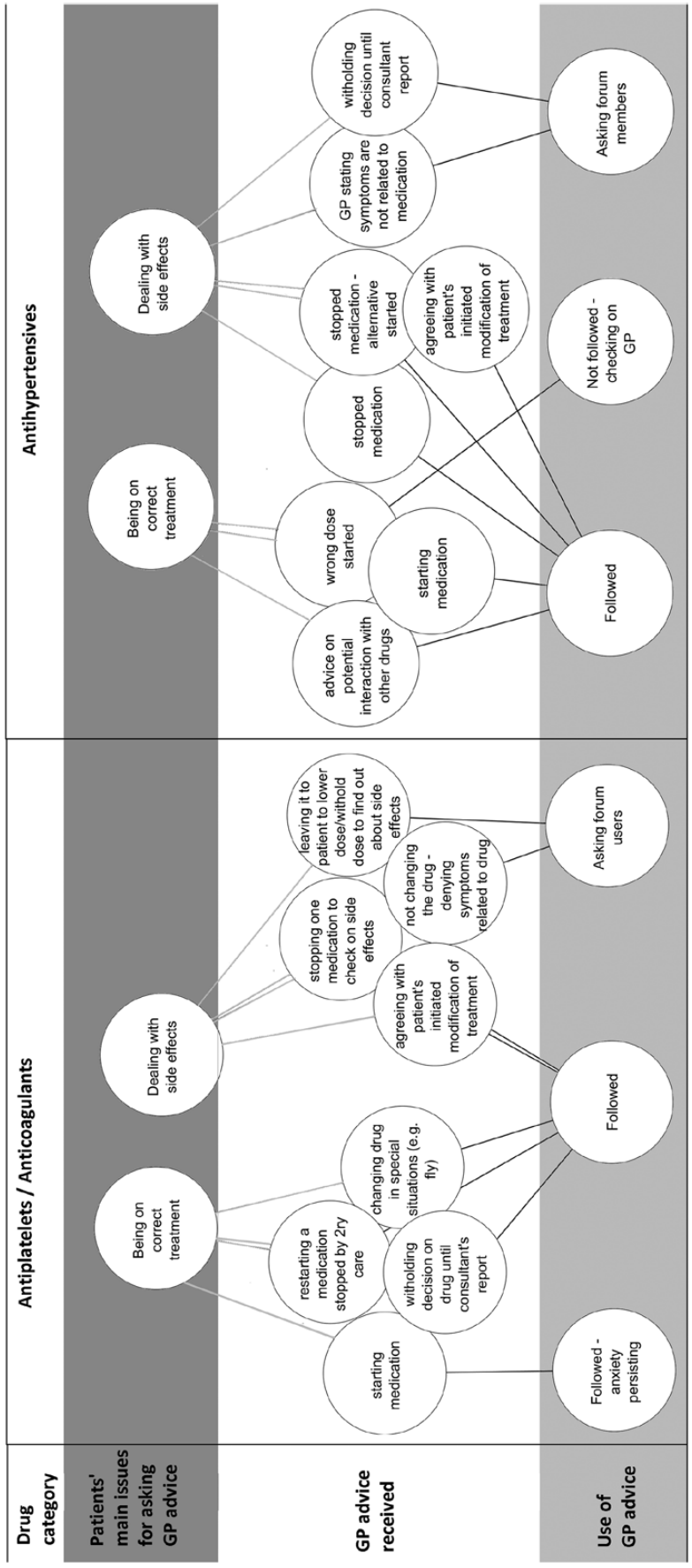

Figure 2. Thematic analysis about GP advice on antiplatelets/anticoagulants and antihypertensives. In horizontal, themes emerging according to: patients' main issues for asking practitioners' advice (dark grey background), practitioners' advice received on secondary prevention medications (white background) and patients' use of practitioners' advice (light grey background). In vertical, themes grouped according to category of secondary prevention medication.

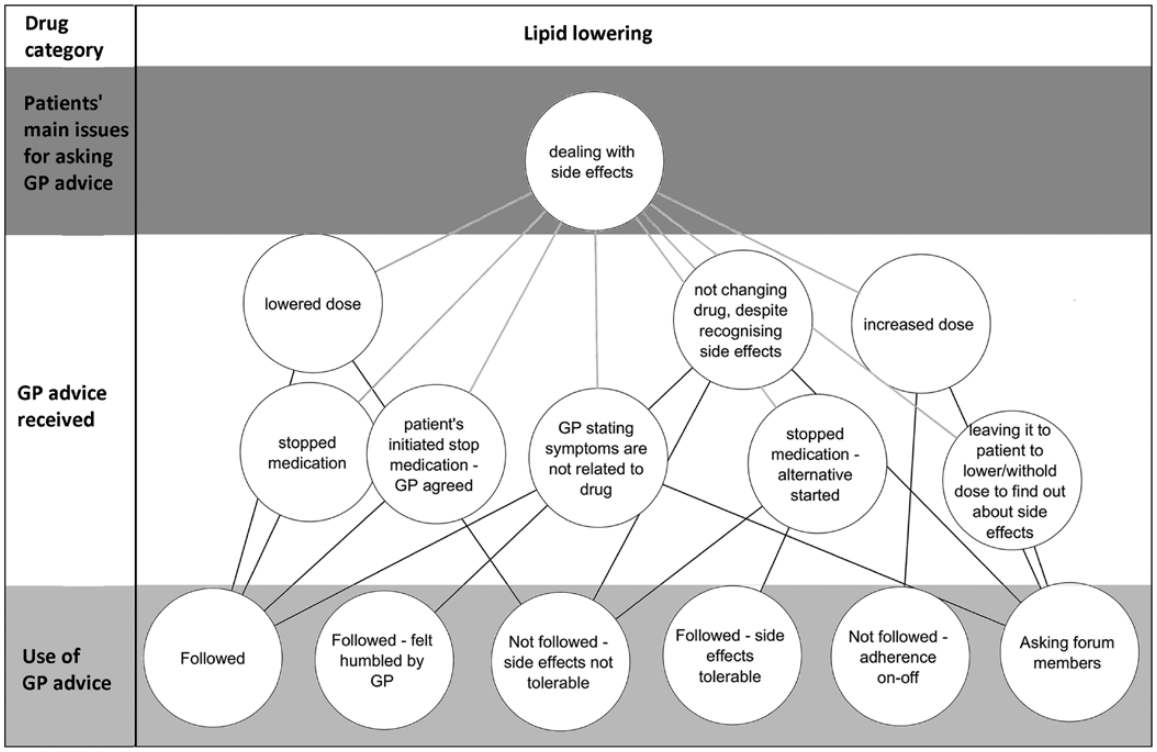

Figure 3. Thematic analysis about GP advice on cholesterol lowering medications. In horizontal, themes emerging according to: patients' main issues for asking practitioners' advice (dark grey background), practitioners' advice received on secondary prevention medications (white background) and patients' use of practitioners' advice (light grey background).

A man wrote about recently having more leg and foot pain plus tremor on his left hand when typing, sleeping badly as well and neck pain on right side. He said he had to work as he had his own company and his partner needed his help. He was on aspirin, statin and ramipril. He had spoken to his GP about whether the drugs were the cause of his symptoms. He requested an X-ray of his neck and said that he needed to keep taking the drugs to avoid stroke recurrences and consequent worsening of his quality of life. (Male, 59 years, age at stroke 56 years, N27).

3) Advice about medications in special situations, like flights, dental procedures or starting an additional treatment (e.g. a painkiller).

A woman said recently she had to have all her teeth out, and her dentist wanted her to stop the aspirin. She contacted her GP about it. (Female, 54 years, age at stroke 46 years, N6).

Patients' use of practitioners' advice

Three main themes were identified for patients' use of practitioners' advice (see Figures 2 and 3): followed, not followed, and asking forum participants. These posts were analysed irrespective of whether they were initiating posts, replies or returning posts written by the same participants who started the conversation.

1) Followed

a. Patients simply stating that they were following their practitioners' advice

A woman said her GP advised her not to stop the aspirin for a dental procedure, and if she was bleeding the dentist would have had to cope. She welcomed and followed this advice. (Female, 54 years, age at stroke 46 years, N6).

b. Patients feeling reassured by their practitioners' advice

A woman was replying to a forum participant who was enquiring about potential treatment for stroke-related pains. She described getting a new pain relief medication from her GP in form of a "patch" that dispenses opiate-based pain relief over the course of a week, similar to nicotine patches. She reported that her GP said there were no contra-indications with being on all other medications she was taking for blood pressure, cholesterol and anti-coagulants. (Female, 54 years, age at stroke 46 years, N6).

c. Patients following the practitioners' advice provided secondary prevention medications side effects were made tolerable

A woman described her boyfriend who had a stroke suffering erectile dysfunction and was replying to another participant who also complained about the same problem following stroke. Her boyfriend was on atenolol. His GP attributed the symptom to atenolol and advised a gradual reduction of the tablet dose and eventually stopped it, swapping it to Ramipril and Amlodipine. The boyfriend followed the advice and his symptoms resolved. (Male, 51 years, age at stroke 49 years, N1).

d. Patients remaining anxious about secondary prevention medication after practitioners' advice

A woman said that although her GP had reassured her that being on warfarin reduces her risk of further stroke and she believed this and was taking the drug, she still kept worrying. (Female, age and age of stroke not stated, N13).

A woman talked about her husband being on several antihypertensives following his stroke. He was suffering from erectile dysfunction but his GP said he could not alter or discontinue any drug until he had heard back from the consultant. The couple agreed to wait although they were wishing the GP had done

something to 'speed things up' and make sure that the consultant who was writing the report was actually taking into account the side effect of erectile dysfunction. (Male, age and age at stroke not stated, N38).

e. Patients feeling humbled by the advice received

A woman asked her GP if she could stop taking the statins due to the horrible head pain that was supposed to only last short term but seemed to continue every day. Her GP put her head in her hands and said that she has had a warning and she could not tell her not to take them. The patient felt very humbled and like a 5 year old (Female, current age and age at stroke not stated, N3).

2) Not followed

a. Side effects not tolerable, participants'adherence on-off.

A man described he was 11 months post stroke and just had a cholesterol test with figure at 4.1. His GP wanted to increase his atorvastatin dose to 80 mg from 40 but he was already suffering what he believed were side effects: muscle pain, weakness and generally feeling ill and if he left the statin off for a few days, felt a bit better. He was asking whether anyone could suggest a better statin or have an opinion. (Male, 59 years, age at stroke 56, N27).

b. Side effects not tolerable, participant admitting stopping the medication.

A woman said that she has tried to get her husband's statins reduced, but his GP insisted on giving him 40 mg even though his cholesterol level was only 5.6. 40 mg was making him chronically tired so he just stopped taking them. (Male, 54 years, age at stroke 52 years, N32).

A woman complained suffering from bouts of light-headedness, brain fog, tight feeling across her chest, tingling and pins and needles all over. She stopped taking the Simvastatin and subsequently her GP swapped her to Atorvastatin. However, after taking it for about a week the tingling started again together with a full sensation to her head and neck with a very 'foggy' brain, and tight chest. She declared that at that point she stopped herself taking the Atorvastatin, convinced that statins were having adverse effect on her. There was no mention of her GP being informed. (Female, 52 years, 52 years at stroke, N35).

c. Checking themselves for practitioners' prescribing mistakes

A man was suggesting to another forum participant to try getting a book called British National Formulary, which he could often find in second hand shops as new books were published every year. He explained that the BNF was the guide that the medical professionals use to prescribe medicines, what every drug is for and what dosages are safe. He reported he had caught his GP prescribing the wrong (dangerous) dose of blood pressure pills to his Father-in-law. He concluded that patients should 'keep an eye on them'. (Male, age and age at stroke not stated, N 19).

3) Asking forum participants

A woman talked about her 88-year-old mother who had a brain bleed. She was on tramadol, gabapentin and simvastatin, and now out of hospital. She said that while her mother was in hospital the pharmacist would look at the combinations of drugs daily, and see whether some drugs could be taken down a dose, or up as thought necessary. Because her mother was also on spironolactone and furosemide, she discussed her mother's medication with her GP, though it all seemed a bit hit and miss. The GP said she could drop down a 20 mg on this or that, it seemed down to her to decide, as the pill dispenser. She was also lately suffering from tummy upsets, so she has been trying through trial and error to take out for example simvastatin, as she was on soya milk to reduce cholesterol anyway, to determine if that was the drug causing the symptom. The mother was also on iron tablets. She did ask for a GP review, but was not getting far with that, and most of the side effects on the drug leaflets seemed to indicate diarrhoea. She concluded by saying she was trying to eradicate the suspect drugs and asking forum participants for advice. (Female, 89 years, age at stroke 88 years, N2).

Feedback received by other forum participants

42/69 posts were feedback received by forum participants and revolved around four main themes (see Table 2):

1) Sharing own experience of secondary prevention medications/ practitioners' advice on secondary prevention medications.

A woman replied to a participant hoping the symptoms described were just a one-off like many patients seem to have after a stroke. She empathised that it was frustrating feeling almost back to normal and then suddenly 'feeling rubbish' again. This was the pattern for herself and she had checked with GP whether this could be down to her medications. (Female, age and age at stroke not stated, N13).

2) Sharing own knowledge

A woman replied to a participant who was asking which drugs her mother might be able to stop taking. She explained that statins are taken because the liver produces cholesterol naturally and diet alone will not be as effective. (Female, 54 years, age at stroke 46 years, N6.)

3) Directing to practitioners, often with expectations of practitioners' actions (e.g. practitioner to check whether side effects could be related to medications).

A woman replied to another participant suggesting to discuss symptoms together with all current medications with the GP. (Female, age and age at stroke not stated, N13).

4) Directing to external source of information (scientific or otherwise).

A man suggested to a participant to look up a recent article on the British Broadcasting Corporation website discussing the role of cholesterol in stroke (Male, age and age at stroke not stated, N46).

Table 2. Themes emerging from the feedback received by forum participants, according to secondary prevention medications category

	No. posts	Sharing own experience	Sharing own knowledge	Directing to practitioners	Directing to external resources
Total	42	34	11	15	2
Antihypertensives	10	9	3	5	1
Antiplatelets/anticoagulant	13	10	1	8	0
Cholesterol lowering	27	22	10	6	2

Because most statements were based on personal experience or own knowledge rather than factual information, no false or misleading statements were identified, according to the definition by Esquivel *et al.* (18).

Replies to posts, including the ones about not following practitioners' advice, rather consisted in sharing their own experience of secondary prevention medications, own knowledge on secondary prevention medications and directing participants back to healthcare professionals or external source of information. Posts that did not receive any feedback were focussed on other issues than secondary prevention medications, with practitioners' advice on secondary prevention medications mentioned only incidentally.

Statins received the most complex feedback (see Table 2, Figure 2 and 3).

Two 'super users' contributed to 36% of feedback posts (a man and a woman, who wrote a total of 4932 and 978 forum posts, respectively). Their advice revealed appropriate understanding of secondary prevention medications and a good rapport with their practitioners.

Discussion

Summary

The online forum was a source of information on the use of practitioners' advice on secondary prevention medications and shed light on the role of peer-to-peer conversations in checking experiences and advice received from professionals. These data suggest that side effects of secondary prevention medications, and statins in particular, cause anxiety and resentment in some patients, and their concerns are not always addressed by practitioners. Patients admitted suboptimal adherence or stopping taking statins after 1 or 2 practitioners' consultations. Educating patients in advance about side effects and the potential need of several attempts to find suitable treatment, in addition to offering a follow-up after medication changes might be considered, in particular for statins. Follow-up might also be helpful when the advice consists in persisting with secondary prevention medications despite side effects. Forum feedback was appropriate and supportive of the practitioners' advice received. No false or misleading secondary prevention medications posts were identified in this study context.

Strengths and limitations

This is the first study that used online forum data to explore how patients use practitioners' advice on secondary prevention medications after stroke. A strength of this work lies in the self-initiated nature of the data provided by online fora and the possibility to analyse patients' perspectives at the time they actually were experiencing issues with secondary prevention medications and asking/receiving practitioners' advice. Such data are less likely to be affected by self-presentation, reactivity and recollection biases and by the influence of the researcher's agenda (23). Moreover fora allow collection of data from participants who might not take part in traditional research studies and from a wide geographical location. A main limitation of this approach is the inability to ask follow-up questions to participants. Information about participants such as age at stroke and sex was limited to what was revealed within their posts. Forum participants were younger compared with most patients with stroke, therefore the views on practitioners' advice on secondary prevention medications by older patients might be under-represented. Some users might have use the word 'doctor' to refer to their practitioners, while our search was limited to posts including the word 'GP', therefore might have missed some relevant conversations. Forum data originated either from a population of stroke survivors who were 'computer-literate-online-forum-users' (a selected population of stroke survivors) or from family members of patients with stroke (representing more widely the population of stroke survivors who might not be computer literate. Sixty percent of all Talkstroke users were family members rather than patients with stroke) (17). While we could analyse the feedback of forum participants, we could not analyse how patients with stroke and their carers reading but not taking part in the forum were affected. There can be up to 26:1 readers per author of a forum message (24) and forum posts can be retrieved and read from looking up keywords in search engines like Google, without the need of registering or accessing the forum itself.

The posts analysed dated between 2004 and 2011, secondary prevention medications practice and medications themselves have changed over the years, and the practitioners' advice received by participants may not reflect current practice. We were not able to assess the change in patients' use of secondary prevention medications or practitioners' advice over the 7 years span, as the date of posts was not available to us. The forum was moderated and some of the posts might have been removed or affected by the moderation process.

Comparison with existing literature

Previous studies have shown a decline in uptake of secondary prevention medications after stroke, with higher rate of discontinuation of statins compared to other secondary prevention medications (4–7). Younger age and concern about medication have been associated with non-adherence (9,25), in agreement with our results. When practitioners' advice was sought about side effects, patients appreciated practitioners' attempts to address the issues, provided side effects were resolved or made tolerable. When side effects were still not tolerable and active measures were not taken by the practitioner dissatisfaction was evident. This is in keeping with a previous study that showed that inadequate consideration of patients' information needs, engagement with healthcare professional and follow-up and monitoring were barriers to adherence to secondary prevention medications (13). Indeed a systematic review of trial interventions including a component to address adherence to antihypertensives after stroke are associated with improved blood pressure control (26). Interestingly patients who decided to stop taking statins did so after only one or two consultations, giving the impression they felt that the number of options for adjusting treatment was limited. Most patients who were not satisfied with their practitioners' advice turned to other forum participants to receive information and support. This strategy seemed successful, considering the number of patients who wrote back thanking for the feedback received, as previously shown (17). Research on online networks suggests that forum members with high number of connections with other participants play an important part in the success of online fora (27). The 'super users' identified in this study provided a significant proportion of the feedback to other participants, in keeping with these findings. The good rapport of these super-users with their practitioners and their appropriate knowledge about secondary prevention medications played an important role in the ability of the forum to identify and provide feedback on inappropriate information and health behaviours in the context of secondary prevention medications.

Unaddressed fear of stroke recurrence emerged from this study, in keeping with previous reports (28).

Data about practitioners' advice on dealing with non-intentional non-adherence factors like forgetting or poor tablet

routines were not retrieved within our data, despite this being a recognised important factor affecting overall adherence after stroke (8).

Implications for research and practice

This study offers interesting insight into shared decision-making in patient-centred healthcare. According to Elwyn *et al.* (29) model, there are three main steps for shared-decision making: introducing choice (choice talk), describing options (option talk) and helping patients explore preferences and make decisions (decision talk). This process is called 'deliberation' and allows patients to become aware of choices available, understand their options and have the time and support to consider what matters most to them. This may require more than one clinical contact not necessarily face-to-face and may include the use of decision support and discussions with others (29). According to this framework, the results presented here suggest a number of areas for practitioners' improvement in the shared-decision making process. While generally themes emerging from GP advice show that practitioners considered patients' issues with medications, offered alternative treatment choices and acted to modify treatment, this was not always the case (see Figures 2 and 3). The lack of being offered options about treatment or education about medications side effects, ended up in patients stopping secondary prevention medicines or in an on-off adherence. Patients might benefit of more practitioners' time and the use of decision support tools to understand their options and might need multiple treatment modifications (>2) to address side effects, in particular for statins. Advising patients to contact the practitioner if issues do occur even after multiple treatment adjustments is advisable. More attention could perhaps be paid to eliciting and listening to patients' anxiety about stroke recurrence and providing reassurance that patients are on the recommended treatment.

Following up patients (even just by telephone) after any change in treatment or after advice on persisting with secondary prevention medications could ensure issues have resolved. Although deliberation may, in part, be done outside the clinical encounter, often patients wish to consolidate their views with a trusted clinician (29). A good relationship with a trusted clinician through shared decision-making may also make the patient feel confident enough to keep sharing problems with medication side effects or non-adherence. There is a time window when patients experience issues with secondary prevention medications when practitioners' intervention may improve persistence.

Patients often want to discuss options with others. Rapley has referred to this need to talk to others, at different times and places, as a 'distributed' deliberation process. Recognizing this need, and allowing time for it, is a cornerstone for effective shared decision making (30). In this study, feedback received by other forum participants facilitated this distributed deliberation process and shared decision making. Forum participants' feedback did not include incorrect or misleading statements, but rather provided peer support and underlined the central role of practitioners in managing secondary prevention medications. This hints that this online patient community was successful and raises questions as to whether online peer support may itself be effective in improving outcomes after stroke.

Considering the ease, low-cost and advantages of obtaining patients' information from online fora, more attention could be paid into studying health related issues using data from online communities.

Conclusions

While confirming previous research, this study of peer-to-peer online conversations offers a novel window to explore problems patients and carers encounter with secondary prevention medications and how these might affect their adherence. Side effects of medications, in particular statins may cause anxiety and resentment in some patients, and their concerns are not always addressed by practitioners. Interestingly, feedback from peers online was appropriate and supportive of the practitioners' advice received.

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Declaration

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Conflict of Interest: none.
Ethical approval: the Stroke Association handed over the archives to ADS with permission to use the data for research purposes. To protect the identity and intellectual property of forum participants, we chose not to use quotes, despite this being normal practice in qualitative research. Instead, we used descriptions of quotes throughout the text (31).

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