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Medication-taking after stroke: a qualitative meta-synthesis of the perspectives of stroke survivors, informal carers, and health professionals.

Running head: Medication-taking after stroke

Article category: systematic review

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Key messages

- Medication adherence is often suboptimal after stroke.
- Interventions to improve medication adherence have limited effectiveness.
- The burden of 'medicines work' is substantial and multifaceted.
- It relies on trust between stroke survivors, carers and health professionals.
- Trust in the benefits of medicines themselves is also important.

Abstract

Background

Lifelong secondary prevention medication is recommended after stroke or transient ischaemic attack. However, poor medication adherence and persistence, which lead to suboptimal health outcomes, are common, but the reasons for this are not well understood, mainly because there have been few studies reporting adherence barriers in stroke survivors.

Objective

The aim of this review was to undertake a meta-synthesis of qualitative studies of medication-taking after stroke. Outcomes of interest were: lived experiences, views and beliefs, and strategies and solutions used by community-dwelling stroke and TIA survivors, informal carers and healthcare professionals in relation to medication taking.

Method

The review protocol was registered on PROSPERO (CRD42018086792). A search of online bibliographic databases was performed using key search terms of stroke, persistence, adherence and medication for years 1980-2018. Citation tracking was also carried out. Studies using qualitative or mixed methods were included. Systematic data extraction and synthesis were conducted using a meta-ethnographic approach.

Results

Twelve studies were eligible for inclusion, with a total of 412 participants, two-thirds of whom were stroke survivors, ranging from 1 month to over 20 years post-stroke. Third-order themes identified were 'Medicines Work' – Information Work; Health Care Work; Carer Work; Emotional Work; Practical Work; and an underpinning theme of Trust. However, many studies had significant methodological weaknesses.

Conclusions

This synthesis suggests that the burden of 'medicines work' after stroke is substantial and multifaceted. Its successful undertaking depends on mutual trust between stroke survivors, carers and health care professionals, and trust in the benefits of medicines themselves.

Key words

Medication Adherence; Patient Experience; Qualitative Research; Secondary Prevention; Stroke; Systematic Review.

Background

Survivors of stroke or transient ischaemic attack (TIA) need several long-term medications for optimum secondary prevention¹ of recurrent stroke or other vascular disease (coronary artery and peripheral vascular disease), in addition to medication for any comorbidities. Adherence to secondary prevention medication reduces the risk of stroke recurrence by around 80%². Poor post-stroke medication adherence (MA) is, however, a common and clinically important problem³. Two-thirds of stroke survivors need medication advice at 6-9 months⁴, less than half feel sufficiently informed about stroke prevention⁵, and many have other unmet needs in relation to medication management⁶. There is limited evidence for the effectiveness of interventions to improve secondary stroke prevention⁷, and although a number of national clinical guidelines for stroke include recommendations to support MA, these are mainly based on consensus^{1,8,9}.

A better understanding of the barriers and enablers of MA could lead to the design of effective and feasible interventions which would have far-reaching effects on health¹⁰. Interventions which are not grounded in this way are likely to have limited effectiveness¹¹. Research priorities for MA support (for any condition) include the evaluation of intervention strategies targeted to specific problems and subgroups¹². However, people's experiences of the barriers and enablers of MA after stroke might be very different from those affecting the general population or those with other clinical conditions, because of such factors as the presence of residual physical or cognitive neurological disabilities. It may also be important to consider the presence of common comorbidities such as diabetes mellitus or coronary heart disease, and the additional medication needs imposed by these conditions. It is thus important to understand the perceptions and experiences of stroke survivors, informal carers, and health care professionals (HCPs) in relation to the barriers and enablers which may affect post-stroke MA, in order to provide appropriate support and to develop evidence-based interventions for future evaluation. Reviews have previously been undertaken of studies evaluating

the effectiveness of interventions to support MA after stroke⁷, and of quantitative studies of predictors of MA after stroke¹³. Other reviews have synthesised the qualitative literature on related, non-stroke-specific topics such as people's beliefs and attitudes to taking statins¹⁴, patients' and carers' knowledge, attitudes and beliefs about medication adherence¹⁵, medication-related burden¹⁶, and medication taking in coronary artery disease¹⁷. However, there are no published syntheses of the qualitative literature exploring the views and experiences of stroke survivors, carers and HCPs on this topic.

The objective of this review was to undertake a qualitative meta-synthesis of the evidence base exploring the views and lived experiences of community-dwelling stroke and TIA survivors, informal carers and healthcare professionals in relation to medication taking after stroke.

Methods

Search strategy

An initial unpublished search of the literature, yielding 4 studies, was undertaken in 2013 and repeated for this review. The search strategy was developed from a scoping review and from the Cochrane Stroke Review Group short form search for stroke. Specific terms relating to secondary prevention, adherence, persistence, and medication were used to search relevant bibliographic databases (Medline, Biomed Central, CINAHL, AMED, EMBASE, psycINFO, British Nursing Index, Web of Science, NLM Gateway, PharmWeb and Bibliomap) for literature published from 1st January 1980 to 18th January 2018. (See Supplementary file 1 for the full search strategy for Medline.) Forward and backward citation tracking was undertaken, including published systematic reviews relating to general medication taking, and reference lists of included articles. Key policy documents, websites and grey literature were also searched.

Inclusion and exclusion criteria

Development of the inclusion and exclusion criteria were informed by the initial scoping review, which suggested that available studies used a range of qualitative methodology, and often included the views and experiences of carers and HCPs as well as stroke survivors themselves. Articles were eligible for inclusion if they met the following criteria:

Population: Community dwelling stroke or TIA survivors, their informal carers (e.g. family members), and any primary or secondary care HCPs who prescribe, advise or otherwise support people in medication taking after TIA or stroke.

Exposure: Being prescribed, or being involved in the prescription, supply, or support in relation to, medication after TIA or stroke, for secondary prevention or any other co-morbidity.

Outcomes of interest: 1) Lived experiences of community-dwelling stroke and TIA survivors, informal carers and healthcare professionals in relation to medication taking after stroke. 2) Views and beliefs of community-dwelling stroke and TIA survivors, informal carers and healthcare professionals to barriers and facilitators of medication taking. 3) Strategies and solutions used by community-dwelling stroke and TIA survivors, informal carers and healthcare professionals to promote medication taking.

Eligible study designs included: qualitative studies; mixed method studies that reported some qualitative data relating to the outcomes of interest; studies including heterogeneous samples of people after stroke/TIA and those with non-stroke conditions if at least some stroke/TIA-specific primary and/or secondary data was reported.

Articles were ineligible for inclusion if they were: published only in abstract form; studies with no qualitative component; data related only to in-hospital or institutional medication taking; non-stroke/TIA population; **not published in the English language, due to lack of resources for translation.**

Data screening and selection of studies

Titles and abstracts were reviewed independently by pairs of reviewers against the inclusion/exclusion criteria. Full texts of potentially eligible studies were then retrieved and independently assessed by pairs of reviewers to identify the final studies for inclusion. Manual searching of the reference lists and citation tracking of included papers was conducted to identify any further potentially relevant studies. All qualitative studies that met the inclusion criteria were included regardless of epistemological underpinnings, as is common in the synthesis of health research¹⁸. Disagreements between reviewers were resolved through team discussions.

Data Extraction

Data were independently extracted by pairs of researchers using a bespoke data extraction form to ensure consistency. The form was initially tested on 3 studies and modified as necessary. Only data from the qualitative component of any mixed methods study, and only stroke-specific data from studies with heterogeneous stroke/non-stroke data, were included. Key information extracted from each of the primary studies included: bibliographic information; details of setting and location; population; research questions or aims, development of the interview schedule or other tools, data collection methods, data analysis methods, theoretical framework, and primary or secondary data relating to the outcomes of interest.

Data Synthesis

The meta-synthesis technique described by Noblit and Hare¹⁹ was used to synthesise the qualitative data, enabling collation and comparison of the evidence across the studies whilst preserving the meaning as interpreted by the original authors. First order constructs, as presented by the authors of the primary studies in the form of direct quotes from study participants were extracted and tabulated by authors 1-4. Second order constructs comprised interpretations, themes or statements developed by the primary studies' authors in response to the first order constructs. Common and contradictory themes were explored across the studies. Using an inductive approach, the review team then developed third order constructs after combining and exploring first and second order

constructs to elicit an explanatory framework for the reported findings. At each stage of data synthesis, the team discussed and reached consensus on their interpretations.

The quality of the included studies was appraised using Walsh and Downe's criteria²⁰. Pairs of researchers independently assessed each included study and then discussed their ratings to reach consensus. In addition to the published domains for data appraisal, we added an appraisal of the reporting of patient, carer and public involvement (PCPI) in the studies' design and conduct, because we felt that its increasing recognition as an essential component of high quality and ethically sound health care research warranted its inclusion. As is common practice in qualitative meta-synthesis, studies were included irrespective of their overall quality.

The research team included health services researchers with expertise in clinical nursing (authors 1 and 3) as well as expertise in systematic review (authors 2, 3, and 4). The first author also holds a prescribing qualification and has led (with author 3) a qualitative study exploring stroke unit nurses', stroke survivors' and carers' views and experiences of managing medication early after discharge.

This study was registered on PROSPERO (CRD42018086792) at <https://www.crd.york.ac.uk/PROSPERO>. The reporting of this qualitative evidence synthesis is in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA)²¹ (see Supplementary file) and the ENTREQ reporting guidelines for qualitative synthesis²².

Results

Our search strategy initially yielded 971 articles. Following exclusion of duplicates, and screening of the title, abstract or complete article, 12 studies met the inclusion criteria. The PRISMA flowchart (Figure 1) illustrates the flow of studies through the synthesis. Table 1 summarises the included studies.

Study participants, design, and quality

The twelve eligible studies included a total of 412 participants, of whom 271 (66%) were stroke (246) or TIA (25) survivors, 106 (26%) were carers and 33 (8%) were HCPs or others; two were unknown. The time points of data collection were reported heterogeneously and ranged from 1 month to more than 20 years post-stroke.

There were nine qualitative studies^{23,24,25,26,27,28,29,30,31} and three studies utilising mixed methods^{32,33,34}. Nine studies utilised purposive sampling^{23,25,26,27,28,29,30,32,34}, and three utilised convenience sampling^{24,29,33}; some aspects of sampling were poorly justified. Methods included semi-structured interviews^{24,25,26,27,29,31,32,33}; semi-structured interviews and focus groups^{23,34}, and analysis of on-line 'chat room' discussions^{28,30}.

Nine studies were assessed as being of moderate quality and three studies were assessed as being of weak quality. Common limitations in the studies included lack of an appropriate theoretical framework, absent key participant data (e.g. age, time since stroke), lack of data saturation, absent participant validation, ethical concerns, and failure to report or consider divergent views. Indeed, one study²⁴ excluded the views of one interviewee (the only male participant) because his views were divergent. In most studies the professional background of the researchers was not explicitly reported, and the identity of the member or members of the research team who conducted the data collection was unclear, which limited considerations of reflexivity in this synthesis. Only two studies reported any PCPI activities, namely a formal PCPI group²³ and the incorporation of stroke survivor feedback about the interview schedule²⁷.

Location of Studies and Types of Participants

Each study was conducted in a single country, including the UK^{23,26,27,28,29,30,31,32,33}, USA²⁴, France²⁵ and Ghana³⁴, the latter being the only low or middle income country (LMIC) represented. Participants included stroke survivors only^{29,31,32,33}; stroke survivors and carers^{23,26,28,30}; stroke survivors, carers and healthcare professionals^{25,27}; stroke survivors, carers, community leaders and healthcare providers³⁴, and carers only²⁴. Where demographic information for stroke survivors was reported^{23,25,27,28,29,30,31,32,33} the mean age was 63.1 years (range 17-93); with 45% being female. Only one study²⁵ reported carers' ages (mean 60 years, range 40-78). Four studies reported participants' ethnicities^{24,29,31,33}, of which only one²⁴ reported the inclusion of participants of non-white ethnicities.

Themes identified

Two overall third order themes: Doing Medicines Work, and Trust, were developed from the first- and second-order themes reported. Doing Medicines Work encompassed several types of work; *Information work; Healthcare work; Carer work; Emotional work and Practical work*, all of which were underpinned by Trust in HCPs, others, or in the medicines themselves. These themes are represented schematically in Figure 2.

A synopsis of each theme is provided below, and exemplar first-order quotes for each theme and sub-theme are given in Table 2.

1. Information work. This subtheme includes all the work that stroke survivors do to obtain, understand and evaluate information about their medicines, such as the reason for the drug or drugs, the underpinning pharmacological and evidence base, and knowledge about how to take it. *Positive examples* of information work included HCPs taking time to explain the medication, the provision of written information by HCPs and their responsiveness to questions. However, many stroke survivors and carers reported a *lack of information provision* and of discourse around medications. Preferences for written or verbal information varied. There was also a *need for ongoing*

information, especially when medication brands were changed. Stroke survivors relied on visual cues about their medication, such as its colour, shape or packaging, but HCPs did not volunteer information about this which led to confusion and further information seeking by the stroke survivor.

2. *Healthcare work*. This subtheme includes the work that stroke survivors undertake to engage with health care services in order to obtain their medicines, arrange and attend monitoring and medicines review. It also includes the reciprocal work performed by HCPs and the interactions between stroke survivors and HCPs. *Negative aspects of healthcare work* included dislike of the need for monitoring such as blood tests for vitamin K antagonists (warfarin), and the 'kerfuffle' of arranging medical review appointments, which were seen as a scarce resource. This could lead to a total lack of ongoing medication support, as with the stroke survivor who had not seen their GP in the 14 months since their stroke. Even when ongoing healthcare advice was obtained it might have perceived negative consequences such as an additional medication being prescribed. However, there were some examples of *stroke survivor-centred healthcare work* where HCPs were responsive to stroke survivors' and carers' concerns and difficulties with medication.

3. *Carer work*. This subtheme includes the work that informal carers (family members, friends or neighbours) perform to assist the stroke survivor with any other type of medicines work. The importance of carer work was referred to by stroke survivors and HCPs as well as carers themselves. Many examples entailed *organising the medication*, whereby carers took responsibility for obtaining medication supplies and establishing a system for the stroke survivor to be able to independently take their medication, but this could lead to errors if the carer was then not available. Carer work could also include *overseeing medication-taking* where direct supervision was felt to be needed, and facilitating access to HCP support. Interactions between stroke survivors and carers about the

medication also fell under this theme, and often included *conflicts between the stroke survivor and carer*.

4. Emotional work. This subtheme includes the motivational work that stroke survivors and carers perform in relation to long-term medication taking. The *perceived necessity* for taking medication was framed in terms of *fear of having another stroke*, which was felt to have serious or potentially even fatal consequences. HCPs also recognised that MA was contingent on the stroke survivor understanding the risk of stroke recurrence. Some stroke survivors were unconcerned about missing medications occasionally. They also expressed *concerns about taking medication*, including a dislike of taking medication, particularly multiple medications, not being 'back to normal', stigma and embarrassment, and worries about potential physical harm such as side effects. Very few HCPs mentioned this emotional work that stroke survivors performed; one HCP even took a protective stance by suggesting that HCPs tended to avoid talking about the necessity for medication with stroke survivors as they were 'already anxious'.

5. Practical work. This subtheme includes a range of direct and indirect activity which is necessary for the stroke survivor to take their medication. It included *logistical and technical work*, including organising, storing, and keeping track of doses taken as well as the act of self-administering the medication. It also included dealing with difficulties caused by physical or cognitive *sequelae of stroke* that affected medication-taking. Successful medication adherence entailed work to *evolve and maintain a routine*. This often relied on interaction with other people, notably carers, and strategies and solutions to maintain routines when a change of circumstances threatened to derail medicines taking. Enablers of practical work included the stability of the medication regime and of the stroke survivor's daily routine; barriers included the need to *modify the routine* and the complexity of the regime. *Affordability* of medication for stroke survivors was a concern in two non-

UK studies, although one UK study also discussed the impact of cost-saving measures within the National Health Service on the availability of specific brands of medication.

6. *Trust*. This theme encapsulates the trust that stroke survivors and carers have to develop in the efficacy of the medication in terms of its potential benefits. Trust could be hampered by the *imperceptible benefit* conferred by medications for stroke prevention, whereby efficacy could ultimately be evaluated only by the continued non-recurrence of stroke. The concomitant reduction in risk of coronary artery or peripheral vascular disease was not noted by any participants. However, some participants expressed different degrees of *trust in the efficacy of specific medication*. Where they readily understood the mechanism of action, or they had evidence from a surrogate endpoint such as blood pressure reduction, this contributed to their trust in the efficacy of that medication. Medicine-taking was also mediated by *beliefs about healthcare*, including trust, or lack of it, in individual practitioners and in the healthcare system as a whole. Notably in the one study conducted in a LMIC, there was a lack of trust in modern medicines.

Conclusions

This qualitative synthesis has identified the various types of medicines work reported in the literature that are performed by stroke survivors, carers and HCPs in order to establish and maintain a medication regime after stroke. This complex medicines work and the underpinning need to develop trust are likely to constitute a substantial treatment burden, regardless of the severity of the stroke.

There are some areas of this body of literature where high quality evidence is particularly scarce. These include the views of carers, even though 7 of the 12 included studies recruited at least some carers, which is noteworthy given the increasing recognition of the value of carer support in many

aspects of life after stroke and in MA generally. Data about the impact of the physical and cognitive sequelae of stroke on people's medication adherence are also scant. It is unclear whether this represents absence of problems in the population studied, given that they may have been younger and less disabled by their stroke than the general stroke population, or is due to the studies' designs and content.

Our comprehensive search strategy enables us to suggest with confidence that we have included most studies published in English up to January 2018. As with any review, publication bias may have influenced the results³⁷. We limited the search to studies published in English, and 10 of the 12 studies were from Anglophone countries, with only one being conducted in a LMIC, and with each included study being conducted in a single country. Some of the issues identified (e.g. access to and cost of medications) may be highly context-dependent due to international variations in the organisation and funding of health care, especially given the preponderance of studies from the UK and the scarcity of studies from LMICs.

Given the complexity of 'medicines work' and the inherent resistance to taking medicines after stroke that is highlighted by this review, it is perhaps not surprising that it has thus far proved difficult to design interventions that are effective in improving MA and clinical outcomes⁷. Such interventions would need to take account of diverse and unique sets of predictors of and barriers to MA which affect different stroke survivors in order to be effective. Although some of these barriers have been identified in observational studies¹³, it is not clear who is most at risk of poor MA, nor what types of interventions are most suited to which individuals. This individualisation of medicines support is not easily captured in a study protocol, practice guideline or manual. Furthermore, the importance of trust as a keystone to MA after stroke underpins the role of the individual stroke survivor/health professional partnership in the provision of tailored support. While it may be a relatively simple task to identify, and formulate a plan to overcome, some barriers to MA after

stroke (for example, problems with manual dexterity), it is perhaps more difficult to identify and address the complex issues of trust which underlie much intentional non-adherence, particularly as stroke survivors may not wish to jeopardise their working relationship with HCPs by expressing lack of trust in their treatment. The importance of this partnership may also underlie some of the problems with the implementation of potentially useful interventions into everyday practice, because the stroke survivors who have participated in clinical trials and the development of interventions are not necessarily representative of the wider populations of interest in terms of their beliefs about, and trust in, health care interventions.

Our categories of 'medicines work' align to some extent with previously described elements of treatment burden in stroke²⁶. The need for trust in MA after stroke also aligns with the concepts of necessity and concerns which underpin much thinking around medication adherence³⁵. Trust in medicines will be present when the individual's perception of their necessity outweighs any concerns they may have. It may be highly context-dependent, as illustrated by the presence of trust in traditional healers and lack of trust in 'western' medicine described in one included study³⁴. The lack of trust in medicines after stroke also concurs with findings from a synthesis of medicine-taking across all health conditions that people are reluctant to take medicines and generally prefer to take as few as possible³⁶. Some of the findings of other recent relevant reviews also resonate with the themes presented here. In studies of people's beliefs and attitudes to taking statins¹⁴, trust in the efficacy of the medication and in HCPs were important, and in studies of medication taking in coronary artery disease¹⁷, working relationships with prescribing clinicians were critical. Across all health care conditions, a general review of patients' and carers' knowledge, attitudes and beliefs about medication adherence¹⁵ found that beliefs about medications, family support, and the role of HCPs were important, and a review of medication-related burden¹⁶ suggested that patients' lived experiences of medicines and associated treatment burden needed to be appreciated by HCPs.

This review of specific barriers, facilitators and predictors of medication persistence and adherence post-stroke has identified many gaps and quality issues in the literature. Of particular note, there are few studies which covered the period early after stroke when people are adjusting to their diagnosis and their new or altered medication regime. The available literature focuses almost entirely on the experiences of stroke survivors in countries in the global North, with only one study conducted in a LMIC and only one further study reporting the inclusion of any non-caucasian participants. Although carers and HCPs constituted 26% and 8% respectively of the participants across all 12 studies, the experiences of carers, in particular, were only reported superficially. The sole study which focused only on carers was assessed as poor quality. Further high-quality studies on this topic should endeavour to address these gaps in the literature.

Many of the issues discussed here are not necessarily specific to stroke, and might also apply to people taking long-term medication for many conditions. Whilst it is important to address condition-specific issues it may also be fruitful to carefully consider the relevance of the findings of similar studies in other conditions and populations, such as cardiovascular primary prevention, secondary prevention in coronary artery disease and peripheral vascular disease, multimorbidity, and polypharmacy, when designing future research studies and interventions. As a corollary, researchers and practitioners in these other fields may wish to address some of the issues identified in this review.

This synthesis illustrates strongly that the burden of medicines work after stroke is substantial and multifaceted, and depends on mutual trust between stroke survivors, carers and HCPs, as well as trust in the benefits of medicines themselves. To better support stroke survivors, HCPs working with stroke survivors need to consider ways in which they can support clear information exchange, minimise the work for patients in accessing medication support from the health care system, help carers to be engaged in supporting the stroke survivor, address people's beliefs and concerns about

their medication and the risk of recurrent stroke, and develop individualised strategies to address practical problems experienced by stroke survivors in relation to taking medication.

Declarations

Ethics: No ethical review was required for this work.

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Conflicts of interest

The authors declare that they have no conflicts of interest.

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Figure 1: Flow chart illustrating the literature search for qualitative meta-synthesis of medication-taking after stroke.

Figure 2. Themes identified in qualitative meta-synthesis of studies of medication-taking after stroke.

Table 1: Summary of studies in qualitative synthesis of medication-taking after stroke, 1980-2018.

First Author, Year and Country	Participants	Time point	Sampling	Data Collection Methods	Mean Age (range)	Female (%)	Topic
Allison, 2008, UK	38 (25 stroke survivors and 13 care givers)	3 to 24 months post stroke	Purposive	25 face-to-face interviews and 4 focus groups	69.5 (37-91) stroke survivors	44% stroke survivors; 62% care givers	Knowledge of risk of hypertension; experiences of receiving information; feedback on the educational resource provided; testing utility of the resource
Bakas, 2002, USA	14 stroke family care givers	Within 6 months post discharge	Convenience	13 telephone interviews; 1 face-to-face interview	NS	100% care givers	5 questions: 1. What is a typical day providing care for a stroke survivor? 2. Do you have any concerns or problems since the stroke survivor has returned home? 3. What have you found helpful in terms of dealing with concerns or problems? 4. What advice would you give someone else in the same situation? 5. If we were to develop a programme to help care givers what would be most helpful?
Bauler, 2012, France	26 (8 stroke survivors, 6 care givers, 4 physicians, 8 nurses) in outpatient and inpatient rehab units	1 month to more than 10 years	Purposive	Face-to-face interviews	53.4 (38 to 67) stroke survivors; 60 (40 to 78) care givers; 28 (23 to 35) health professionals	5 (36%) stroke survivors; 9 (74%) Health professionals	Stroke beliefs, medication issues, patient experience and relationships with healthcare professionals
Chambers, 2011, UK	26 (13 low adhering and 13 high adhering) ischaemic stroke survivors living independently	Within 15 months post stroke	Purposive	Face-to-face interviews	63.5 (NS) stroke survivors	46% stroke survivors	Experience of taking medication and beliefs about medication

Chambers, 2014, UK	28 stroke and TIA stroke survivors living in the community	Three months to 6.5 months post discharge	Convenience	Face-to-face interviews	68.3 (51 to 85)	39% stroke survivors	Aspects of the medication which may change as a result of a switch to another brand of medication; stroke survivors understanding of generic medication and the reasons behind medication switches; the impact medication switches had on stroke survivors medication taking
Gallacher, 2018, UK	29 stroke survivors living in the community and an unspecified number of their carers	2-241 months, mean 68.3 months.	Purposive; from both hospital OPD and GPs	Face-to-face interviews	Stroke survivors - Mean 68 years (range 40-49 to 80-89, exact ages not given)	44.8%	Treatment burden after stroke Factors affecting capacity to cope with treatment burden
Jamison, 2016, UK	28 stroke survivors, 14 accompanying caregivers, 5 GPs	4 months to 18 years; mean 5.7 years	Purposive	Face-to-face interviews	74.0 (61 to 93) stroke survivors	25% stroke survivors	<i>Patient</i> Health and medication since stroke; medication taking. <i>Caregiver</i> Role in managing patient's medication; barriers and concerns; strategies to improve medication taking. <i>GP</i> Treatment for secondary prevention of stroke; strategies to improve medication taking; patient understanding and management; limitations of current regimens for secondary prevention
Jamison 2017, UK	84 (49 stroke survivors; 33 caregivers; 2 not known)	37 (44%) (0-12 months); 25 (30%) (1-5 years); 4 (5%) (6-10 years); 2 (2%)	Purposive	Analysis of on-line discussion posts	58 (32-91) stroke survivors	(45%) female; 7% unknown	The PAPA framework including: (beliefs and preferences) and practical (capability and resources) factors which have an influence on stroke survivors commencing and continuing treatment. Barriers and facilitators of adherence to secondary prevention medications

(11 and 15 years);
1 (1%) (15 years +);
15 (18%) unknown

Kelly, 2011, UK	11 people with dysphagia living independently >60 years (2, 18% stroke survivors)	NS	Convenience	Face-to-face interviews	NS	0%	Medication formulation; information exchange; factors affecting medication adherence; strategies used for swallowing medication
Izuka, 2017, UK	50 (33 stroke survivors, 17 care givers)	Mean 2.3 years	Purposive	Analysis of on-line discussion posts	49.0 (17–88) stroke survivors	54% stroke survivors	Participants engaged in free discussion about any topic.
Nichols, 2017, Ghana	38 (13 stroke survivors, 9 caregivers, 6 faith-based community leaders. Interviews: 10 healthcare providers and hospital administrators)	8 less than 1 year and 5 over 1 year post stroke	Purposive	Focus groups and face-to-face interviews	55.3 (NS) Overall group	64% Overall group	Focus groups: (1) beliefs about HTN and stroke risk factor control, (2) existing self-management strategies and experiences, (3) expectations and preferences, (4) knowledge and (5) impressions of nurse navigators and remote monitoring or mHealth technology. Interviews: (1) current approaches to HTN treatment and stroke risk factor control, (2) perceived gaps in care, (3) cultural competence or communication, (4) knowledge of treatment guidelines, (5) impressions of in-hospital health education, involvement of nurse navigators and home BP monitoring
Souter, 2014, UK	30 stroke survivors with ischaemic or haemorrhagic stroke from acute stroke, rehabilitation or outpatient settings	Within 12 months of stroke onset	Purposive	Face-to-face interviews	69 (32–86) stroke survivors	50% stroke survivors	Questions in relation to condition (stroke); questions in relation to medicines; side effects or worries about medicines; inconvenience/ effects on lifestyle; information provision; support

Table 2: Exemplar first-order quotes from a qualitative synthesis of medication-taking after stroke.

Theme	Exemplar first order quote	Participant	Study
Information work			
Positive examples	'I think that taking the time to explain the prescription to outpatients is really important'	HCP	Bauler 2012
	'...she (the stroke nurse) sent me out some leaflets on things for HRT, and you know, anything I needed to ask her, she was there if I needed to phone her ... my own GP is very good as well.'	Patient	Chambers 2011
	'...the doctors explained to me why they wanted me to take it, and they explained the best time of day to take it. And I have no reason to want to ignore their advice.'	Patient	Chambers 2011
Lack of information provision	'There's a lot of them, I don't know what they're for. I've just always had them.'	Patient	Chambers 2011
	'No, I don't think we've got hardly any information. We haven't ever really had a lot of information about it have we? You just sort of get on with it ... I mean perhaps I haven't ever asked enough but ... I think you should be, told in advance.'	Carer	Jamison 2016
	'I don't know why I take them, but it tells you on each one, you know, what it's for ... I wouldn't say I know what they're for.'	Patient	Jamison 2016
	'You'd get more information out of a leaflet than you do with a person trying to tell you.'	Patient	Souter 2014
Need for ongoing information	'There's one time it's such and such a brand and the next it's another brand, so you get used to seeing maybe a particular colour or shape and then he changes it and you're, 'Which one's which now?'	Patient	Chambers 2014
	'Well, if the chemist gives you another make and the box changes as well... that to me would confuse some people and it makes you think a little bit harder.'	Patient	Chambers2014
	'It was a smaller, a different-shaped tablet and I thought, 'I wonder if it's the wrong thing... I'll go to the chemist,' ... but no, he said, 'It's just a different...' em, what would you say, manufacturer?'	Patient	Chambers 2014
	'What I did notice was that the simvastatin changed colour, changed from a pink tablet to a white tablet, why that was I don't know, but I'm assuming that it's still the same stuff that's inside the capsule... I suppose I'm doing in that case is trusting	Patient	Chambers 2014

	the pharmacist is doing their job properly... ,		
Healthcare Work			
Negative aspects of healthcare work	'There is no way I'm going to take warfarin... and have to go for blood tests... I just hate them... suppose I had to go on a Monday... well once it was over I would start worrying for the next Monday.'	Patient	Souter 2014
	'I should go and see the doctor but making an appointment is such a kerfuffle.'	Patient	Souter 2014
	I should have really made an appointment to go and see her (GP). I haven't seen her since this happened 14 months ago.'	Patient	Chambers 2011
	'I have to take 10 a day now altogether but I went up there [to the practice] to say can I get off some of these tablets, and I come back, and I was on an extra one, so I've not been up since.'	Patient	Jamison 2016
Patient-centred healthcare work	'They changed his medication to cheaper cholesterol and [he] was physically ill. He couldn't cope on it at all, so he went back, and the doctor said, "oh well it was just to try" and they put him back on the others.'	Carer	Jamison 2016
Carer Work			
Organising the medication	'People with family or with a good social support have fewer difficulties in managing their treatment.'	HCP	Bauler 2012
	'He's quite organised now. He made quite a mess of it in the beginning, but we've got him organised now.'	Carer	Chambers 2011
	'...my sister, she's got everything well organised (for me) on my wee meal table.'	Patient	Chambers 2011
	'My son was away. He always makes sure I get my prescriptions and I forgot.'	Patient	Chambers 2011
Overseeing medication-taking	'My wife sorts it out and that's why I don't know so much about it you see she [taps]. She puts them there, I take them and that's it.'	Patient	Jamison 2016
	'The warfarin one, my daughter always makes sure I take it.'	Patient	Gallacher 2018
Conflicts between the patient and carer	'What upsets me is that the doesn't like to take medication or doesn't want to get the prescriptions filled or he has one excuse after another why he shouldn't take the medicine.'	Carer	Bakas 2002
Emotional Work			
Perceived necessity	'I have no choice; if I don't take the medication, I will have a new stroke...'	Patient	Bauler 2012
	'I know I could die if I don't take my medication.'	Patient	Bauler 2012

	'They have to understand that they could have another stroke.'	HCP	Bauler 2012
	'No, I mean I just accept the fact that it's got to be done and it's bad... I'd rather it wasn't, but it's far better than the alternative.'	Patient	Chambers 2011
	'I'm sort of, a little bit annoyed that I've missed them but, no it doesn't worry me. It would worry me if ... I missed them for 3 or 4 days but a day, no.'	Patient	Jamison 2016
<i>Fear of having another stroke</i>	'I could have another one and it scares me.'	Patient	Bauler 2012
	'We don't talk about it (recurrent stroke risk), because they are already so anxious'	HCP	Bauler 2012
<i>Concerns about taking medication</i>	'It's a lot of tablets. At one point I just felt, I felt as if I was dizzy with all these tablets.'	Patient	Chambers 2011
	'I told myself that things will no longer be normal.'	Patient	Bauler 2012
	'On a Sunday I don't take the water one (diuretic) ... everybody looks at you if you've got to waltz to the back of the church to go to the loo.'	Patient	Souter 2014
	'Among the men you notice that they stop taking their medications due to the fear of getting sexual dysfunction...'	not stated	Nichols 2017
Practical Work			
<i>Logistical and technical work</i>	'I only remember to take the others ... if I take them out of the cupboard the night before and leave them on the top. If I didn't take them out, I would probably forget ... because it isn't the first thing that I think of ... when I first get up.'	Patient	Jamison 2016
<i>Physical sequelae of stroke</i>	'I have a problem swallowing... these are quite big ones, these clopidogrel I bite into them, I just resorted to... I bite into them then I take the water or coffee, I manage to swallow the bits...'	Patient	Chambers 2014
	'From a patient's perspective it's usually it's just physically a lot of tablets you have to swallow.'	HCP	Jamison 2016
	'Some of the, the pills are a hell of a trouble, you know the bubble wrap, flipping them out especially with my hands not as strong as they should be.'	Patient	Jamison 2016
<i>Evolving and maintaining a medication routine</i>	'I just do it routinely now. It's just part of when you get up in the morning, what you go through, you know. Have a shower, brush your teeth...'	Patient	Chambers 2011
	'...I forgot to take the pills with me (on a weekend away) but I went down to the chemist, and bought aspirins, but they are	Patient	Chambers 2011

	small aspirins, so I just halved the big aspirins...'		
Modifying the routine	'If I go out in the evening, I make sure I've got my pills in my pill box, ready to be taken.'	Patient	Chambers 2011
	'For example, the aspirin is (now) the same colour as the lisinopril, and the lisinopril's just a slightly bigger tablet. So, I've got to dissolve the aspirin but keep the lisinopril whole, so that's kind of... more an inconvenience than anything else, you know?'	Patient	Chambers 2014
	'There used to be paper at the back [of the packet] and now I am sure some of them are plasticky, and I'm sitting with a knife trying to cut them [tablets] out. '	Patient	Souter 2014
	'Well they've just changed one of them, it's the same stuff only... it's got no days on, most of them have Monday, Tuesday, Wednesday so if I go today and I see Monday's there, I know I've forgotten one ...they've changed one of them and it's got no bloody days on it at all.'	Patient	Gallacher 2018
Affordability	'Now it's like all these other pills and the insulin and the blood sugar monitor. We have to constantly keep buying all this stuff.'	Carer	Bakas 2002
	'Some of the drugs are costly and it is not easy to buy all of them.'	Not stated	Nichols 2017
	'Well, they just say (no), 'Well, it comes out of our budget.'	Patient	Chambers 2014
Trust			
Imperceptible benefit	'They do not feel sick, so they think that if they do not take their medications they will not be sick.'	HCP	Bauler 2012
	'Patients are tempted to stop taking their medications as they no longer exhibit clinical symptoms.'	HCP	Bauler 2012
	'I didn't think at first when I was taking them that they were doing me any good. And I did stop taking them.'	Patient	Chambers 2011
	'I've been taking all that for four years, I might not need it.'	Patient	Gallacher 2018
Trust in the efficacy of specific medication	'I think aspirins are good for you. That's the only one I fancy. Well it thins the blood and I think, well by thinning the blood it flows better and that stops any clots, so I do like to take it. I just don't see why I'm taking other medication, I'm not fat or anything like that. I don't get very high blood	Patient	Jamison 2016

	pressure, and well cholesterol, what is cholesterol?’		
	‘Well, if it was simvastatin I think that would matter. The other ones I think you could miss out a few without affecting my blood pressure.’	Patient	Chambers 2011
	‘Since taking all these medicines my blood pressure has been coming down.’	Patient	Souter 2014
<i>Beliefs about healthcare</i>	‘We have this belief that medicines do not help.’	Not stated	Nichols 2017
	‘I feel that whatever the doctor prescribes, they know what they are doing, and talking about... I’ve got trust in the doctor.’	Patient	Chambers 2011
	‘So, if the doctor says take ten pills a day, I’ll, I’ll do it ... he makes the decision and erm he, he’s the boss man as you might say, who knows what he’s up to.’	Patient	Jamison 2016
	‘He’s the pharmacist and he deals with drugs. He’s bound to know what’s what. He didn’t pass his qualifications just to pop out some pills and say there you are.’	Patient	Souter 2014