Adherence to medication in stroke survivors: A qualitative comparison of low and high adherers

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Objectives. The aim of this study was to investigate factors that may explain variance in adherence to medication in stroke patients.

Design. A qualitative comparison of high and low adherers to medication.

Methods. Thirteen participants, selected from a sample of 180 stroke survivors because they self-reported the lowest adherence to medication regimes, were matched with 13 reporting maximal adherence. All took part in semi-structured qualitative interviews.

Results. Thematic analysis revealed that those with poor adherence to medication reported both intentional and non-intentional non-adherence. Two main themes emerged: the importance of stability of a medication routine and beliefs about medication and treatment. High adherers reported remembering to take their medication and seeking support from both family and health professionals. They also had a realistic understanding of the consequences of non-adherence, and believed their medicine did them more good than harm. Low adherers reported forgetting their medication, sometimes intentionally not taking their medication and receiving poor support from medical staff. They disliked taking their medication, had limited knowledge about the medication rationale or intentions, and often disputed its benefits.

Conclusions. Our findings suggest that appropriate medication and illness beliefs coupled with a stable medication routine are helpful in achieving optimal medication adherence in stroke patients. Interventions designed to target both intentional and non-intentional adherence may help maximize medication adherence in stroke patients.

Stroke is the third most common cause of death in the United Kingdom and is the most common cause of severe physical disability amongst adults (Adamson, Beswick, & *Correspondence should be addressed to Professor Ronan O’Carroll, Department of Psychology, University of Stirling, Stirling, FK9 4LA, Scotland, UK (e-mail: reo1@stir.ac.uk).

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Adherence to medication in stroke survivors

Ebrahim, 2004; Griffiths, Rooney, & Brock, 2005). The National Audit Office estimated in 2005 that the annual cost of caring for people with stroke in England and Wales is around £7 billion per annum (Department of Health, 2005), thus reducing stroke reoccurrence will help cut healthcare costs and so is an important focus for intervention. The risk of a recurrent stroke is 30–43% within 5 years (Warlow et al., 2008). This risk can be noticeably reduced by preventive treatment aimed at lowering blood pressure (all types of stroke) and reducing blood cholesterol (ischaemic stroke) along with anti-platelet and/or anti-coagulation treatment (ischaemic stroke) (Sudlow, 2008). All of these can be achieved by following relatively straightforward medication regimes, but the success of such treatments is determined to a large degree by adherence to medication.

Despite this, only limited data are available on patient adherence to medication intended to prevent recurrent stroke. Sappok and colleagues reported from a follow-up study 1 year after stroke and found that only 70% of patients were still taking cholesterol-reducing treatment (Sappok et al., 2001). Data from the Netherlands revealed that by 1 year after ischaemic stroke, 22% of patients who had been taking oral anticoagulation had stopped, half of whom did so ‘for non-medical reasons’ such as perceived adverse effects or simply because the patient requested to (De Schryver, van Gijn, Kappelle, Koudstaal, & Algra, 2005). Thus, the available data on stroke patients suggest that adherence is often sub-optimal, and that many patients are consequently at a significantly increased risk of a further stroke and/or cardiovascular event.

To date, we are not aware of any studies that have examined adherence to multiple medications in stroke patients. However, there is no reason to believe that stroke patients should demonstrate better adherence than in other chronic conditions requiring polypharmacy. In fact, the reverse is more plausible, given stroke often causes cognitive impairment (such as memory loss) that is known to cause adherence problems (Stilley, Bender, Dunbar-Jacob, Sereika, & Ryan, 2010). It is estimated that in developed countries, only 50% of patients who suffer from chronic diseases adhere to treatment recommendations (World Health Organisation, 2003). A recent illustrative example from the field of cardiovascular disease is provided by the Duke Databank for Cardiovascular Disease for the years 1995–2002, which assessed the annual prevalence and consistency of self-reported use of aspirin, β-blockers, lipid-lowering agents, and combinations of the three drugs in patients with coronary artery disease. Rates of consistent self-reported medication use were sobering, aspirin (71%), β-blocker (46%), lipid-lowering agent (44%), aspirin and β-blocker (36%), and 21% for all three medications. Overall, consistent use was associated with lower adjusted mortality, although in this study, the authors were unable to differentiate patient non-adherence from physician non-prescription (Newby et al., 2006). In a further study of drug adherence and mortality in 31,455 survivors of myocardial infarction who were taking statins and β-blockers, patients were divided into three adherence categories: high, intermediate, and low. After 1 year, compared with the high-adherence group, low adherers to statin therapy had a 25% increased risk of mortality (Rasmussen, Chong, & Alter, 2007). Thus, self-reported adherence in polypharmacy is often suboptimal and this is associated with elevated mortality risk (Albert, 2008).

There is increasing recognition that factors associated with non-adherence may represent both non-intentional and intentional causes (Clifford, Barber, & Horne, 2008). Non-intentional non-adherence represents a patient’s failure to actively remember, or in some cases physically manage, to take their medicine as prescribed. Intentional non-adherence is associated with beliefs about treatment, particularly the perceived necessity of medication versus concerns about possible harmful effects. A synthesis of qualitative
studies of medicine taking also concluded that a major reason for non-adherence is concern about the medication itself (Pound et al., 2005). Pound et al. also suggested that patients are motivated by a desire to minimize their intake of medicines in order to make their regime more acceptable and reduce the risk of negative consequences such as side effects. It seems plausible therefore that the more complex the medication regime, such as in preventive stroke treatment, the more negative beliefs about treatment and its consequences may impact on a patients’ adherence and ultimately their health. Other qualitative research has shown that those who persist in taking medication despite these concerns, balance them against the perceived benefits (Benson & Britten, 2006).

A major risk factor for recurring vascular events or death is non-adherence to medication (Bailey, Wan, Tang, Ghani, & Cushman, 2010), and yet there is currently a lack of information on adherence to preventive medication in stroke patients, particularly those taking multiple medications. We aimed to address these knowledge gaps by attempting to identify factors associated with good and poor adherence in stroke patients. Qualitative interviews were used to explore patients’ knowledge, attitudes, and beliefs regarding their medication, as well as their experiences of taking their medication including any concerns or difficulties that may have arisen, in low and high adherers identified from a larger quantitative survey. Qualitative methods were chosen, as this would enable us to gain a richer understanding of a little investigated topic.

Methods

Participants

Ethical approval was granted by the NHS Lothian Local Research Ethics Committee prior to the study commencing and the research was carried out in accordance with universal ethical principles. When patients attended their first outpatient appointment or were admitted to the Stroke Unit in the Western General Hospital in Edinburgh, they were given the option of being included in a register of potential research participants. A database of patients to be considered for the current study was generated from this register using a filter system based upon the following inclusion criteria: no stroke prior to index event, diagnosed with an ischaemic stroke in the past 15 months, not resident in a nursing or residential home, living within approximately a 50 mile radius of Edinburgh, and having a permanent residential address. In addition, only patients who scored over 13/20 on the Frenchay Comprehension test (Enderby, Wood, Wade, & Hewer, 1987) were eventually included in the study, because of the need for this level of language ability to enable participation in interviews. Standard letters of invitation to participate were sent to patients who were then telephoned 1 week later to ask whether they had any questions or might be interested in participating. If a patient wished to take part, an interview was arranged, to be held in their own home or in a dedicated Clinical Research Facility. Patients were telephoned 1–2 days before the interview as a reminder and to check they were still happy to participate.

One hundred and eighty first-time ischaemic stroke patients, who were approximately 1-year post-stroke, were included in the potential participant pool. This represents 56% of those on the register during the recruitment phase; 14% of those registered could not be contacted; and 36% were either ineligible (according to above inclusion criteria including previous stroke) or declined consent. Only two patients were excluded because their Frenchay scores were <13/20. Thus, 180 participants were screened using the Medication Adherence Report Scale (MARS). The MARS is a self-report measure that
Adherence to medication in stroke survivors

provides a sensitive assessment of drug adherence behaviours (Horne, 2004). It consists of five items, each assessing a separate non-adherent behaviour with respect to medicine taking. The questions in the MARS are specifically designed to reduce social desirability effects. For example, the introduction states, ‘Many people find a way of using their medicines that suits them. This may differ from what the instructions say on the label or what their doctor has said. We would like to ask you a few questions about how you use your medicines’.

From the total cohort of 180 patients, 26 were selected to take part in detailed qualitative interviews. The MARS scale had a clear ceiling effect with the majority (79%) of the 180 participants scoring 24 (34%) or 25 (45%) of 25. Only 13 people had scores \( \leq 22 \) on the MARS total scale. As our aim was to evaluate differences between high adherers and low adherers, we selected the 13 patients who reported the lowest adherence to their medication (MARS total scores ranging from 13 to 22), and matched them on gender, age, and scores (±3) on the National Institutes of Health Stroke Scale (NIHSS) with 13 high adhering patients (all scoring 24 or 25 out of 25). The NIHSS is a standard measure of severity of symptoms in stroke patients. Scores can range from 0 to 42 with higher scores representing more severe symptoms. The majority of patients were matched on age within ±3 years. However, one participant (a low adherer) was notably younger (22 years) than the rest of the sample and hence the youngest available match in the high adherence group (43 years). The 22-year-old did not notably differ from other low adherers on any other measures (e.g., NIHSS, socio-economic status, MARS score, or other quantitative measures listed below) and his responses to the qualitative interview supported rather than disputed the findings from other participants; hence he was included in the current analysis.

The high adhering group consisted of six females and seven males, with an average age of 64.6 years (SD = 14.2, range 43–85 years), and NIHSS scores ranging from 0 to 4. The low adhering group consisted of six females and seven males, with an average age of 61.9 years (SD = 18.6, range 22–88 years) and their scores on the NIHSS ranged from 0 to 5. Both groups were therefore at the low end of stroke severity.

**Measures**

The questionnaire data used in the quantitative survey included the following measures.

*Mini-Mental State Examination (MMSE) (Folstein, Folstein, & McHugh, 1975)*

The MMSE is a brief, valid, and reliable assessment of different components of cognitive function, which is widely used in stroke research. Scores range from 0 to 30.

*Rivermead Behavioural Memory Scale (RBMT) (Wilson, Cockburn, & Baddeley, 1985)*

This is a measure of prospective memory function, consisting of 11 sub-tests of which only two were used: Belongings and Appointment. Scores from these two sub-tests were combined to form an overall prospective memory functioning score.

*The Beliefs about Medication Questionnaire (BMQ) (Horne & Weinman, 1999)*

The BMQ assesses cognitive representations of medication. We report the BMQ-specific subscale to assess beliefs about medication prescribed for patients’ own illness(es). This
has two 5-item subscales representing: (1) beliefs about the necessity of medication (necessity) and (2) beliefs about the danger of dependency, toxicity, and negative effects of taking medication (concerns). High scores indicate greater necessity beliefs or concerns.

Perceptions of risk and benefit
A simplified Likert-style graphical presentation card was presented and patients were asked to indicate (1) their perceived risk of experiencing a further stroke in the next 5 years, and (2) their perception of the benefits of their current stroke prevention medication, following Trewby et al. (2002).

Carstairs index of social deprivation (McLoone, 2004)
This index provides deprivation categories (DEPCAT) based on postcode region of social deprivation in Scotland. Scores range from 1 to 7 and higher categories indicate high deprivation (i.e., lower socio-economic status).

Procedure
Participants were assessed using a semi-structured interview schedule that had been developed in order to obtain patient views regarding their medication adherence. The interviews were constructed to present questions that enhance acceptability of poor adherence and reduce social desirability biases. For example, when raising the issue of adherence we asked, ‘Simply forgetting to take medicines at a certain time or in a certain way is also very common. Is this something you have experience of too sometimes?’.

A trained Research Assistant interviewed patients in a single session lasting around 60–90 minutes. A large part of the interview was dedicated to completing questionnaire data about adherence to medication that have been previously reported (O’Carroll et al., 2008). The current report presents findings from open-ended questions developed to glean patients’ views regarding experience of taking their medicines and their beliefs about medication. This part of the interview lasted around 15–30 minutes. Participants were given a chance to ask questions or to discuss the research before the interview began. It was then made explicit that the interview was confidential, and that all information obtained would be anonymized before being reported. The interview schedule was explained and once informed consent had been received from each participant, the interviews began. All were recorded using a digital voice recorder for subsequent transcription.

Analysis
Interviews were fully transcribed and the content was analysed using a detailed qualitative thematic analysis procedure (Braun & Clarke, 2006). A first analysis of the data was conducted by an independent Research Assistant (JW), who had not conducted the interviews. The analysis involved verbatim transcription of the interviews and the production of initial codes from the transcripts using NVivo software (QSR International). The two groups (low and high adherers) were analysed separately. The transcripts were repeatedly re-read and re-coded in an iterative process, and when saturation of codes from the transcripts was deemed to have been reached, the codes were combined
into broader themes. At this stage, all data were included. Two main broad themes then emerged (as reported below), plus a number of sub-themes. Some sub-themes were discarded at this point due to insufficient data (e.g., ‘old age’ as a sub-theme of ‘remembering versus forgetting’ as it resulted from only two individuals). Themes were then reviewed by re-reading all coded extracts, and further refinement made (e.g., ‘side-effects’ was discarded as a sub-theme of ‘beliefs about medication’ as it did not include any coded extracts not attached to the reported themes). Thematic maps were drawn and themes were defined and named, using the existing literature on intentional and non-intentional non-adherence as a framework. In this initial analysis, the themes were then cross-checked by another member of the research team (RO’C), who was not involved in the interviews.

Following the suggestions of three anonymous reviewers of an earlier draft of this paper, a further iteration of the analysis, following the above procedure, was conducted from scratch by a third researcher (JC). The aim was to validate the themes from the original analysis, further evaluate the differences between low and high adherers within each theme, and also provide a more in-depth interpretation of the data. To this end, low and high adherers were not analysed separately. Instead, once all themes had been defined, the coded extracts for each theme were summarized for first low and then high adherers, in order to facilitate direct comparisons.

Results

Table 1 shows the characteristics of high and low adherers. As the two groups were matched on age and gender and severity of stroke (NIHSS) scores, there were no

<table>
<thead>
<tr>
<th></th>
<th>High adherers</th>
<th>Low adherers</th>
<th>Mean difference (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td>7 male; 6 female</td>
<td>7 male; 6 female</td>
<td></td>
</tr>
<tr>
<td>Living alone</td>
<td>23.1% (n = 3)</td>
<td>46.2% (n = 6)</td>
<td></td>
</tr>
<tr>
<td>Age range</td>
<td>43–85</td>
<td>22–88</td>
<td></td>
</tr>
<tr>
<td>Mean age (SD)</td>
<td>64.9 (14.5)</td>
<td>61.9 (18.6)</td>
<td>2.9 (−10.6, 16.4)</td>
</tr>
<tr>
<td>Time since stroke (mean months)</td>
<td>13.2 (1.0)</td>
<td>13.8 (0.7)</td>
<td>−0.6 (−1.2, 0.1)</td>
</tr>
<tr>
<td>Range of months since stroke</td>
<td>11.9–14.8</td>
<td>12.7–14.7</td>
<td></td>
</tr>
<tr>
<td>Carstairs index of deprivation (mean)</td>
<td>3.4 (1.6)</td>
<td>3.7 (1.6)</td>
<td>−0.3 (−1.8, 1.2)</td>
</tr>
<tr>
<td>Total of different medications per day</td>
<td>6.4 (3.2)</td>
<td>4.9 (2.6)</td>
<td>1.5 (−0.8, 3.9)</td>
</tr>
<tr>
<td>Frenchay test total score</td>
<td>19.0 (0.8)</td>
<td>18.2 (1.0)</td>
<td>0.8 (−0.3, 2.0)</td>
</tr>
<tr>
<td>Rivermead behavioural memory test</td>
<td>9.5 (3.1)</td>
<td>7.1 (3.3)</td>
<td>2.5 (−0.1, 5.0)</td>
</tr>
<tr>
<td>MMSE total</td>
<td>27.7 (1.9)</td>
<td>26.5 (3.5)</td>
<td>1.2 (−1.2, 3.4)</td>
</tr>
<tr>
<td>BMQ specific necessity beliefs</td>
<td>19.1 (2.4)</td>
<td>18.2 (5.0)</td>
<td>0.9 (−2.2, 4.1)</td>
</tr>
<tr>
<td>BMQ specific concerns</td>
<td>11.5 (2.5)</td>
<td>15.9 (5.0)</td>
<td>−4.4 (−7.6, −1.2)*</td>
</tr>
<tr>
<td>BMQ specific necessity minus concerns</td>
<td>7.6 (3.8)</td>
<td>2.3 (2.6)</td>
<td>5.3 (2.7, 8.0)**</td>
</tr>
<tr>
<td>Perceived risk of medication (%)</td>
<td>26.7 (29.6)</td>
<td>44.6 (38.0)</td>
<td>−17.9 (−46.3, 10.4)</td>
</tr>
<tr>
<td>Perceived benefit of medication (%)</td>
<td>86.9 (25.0)</td>
<td>62.3 (33.9)</td>
<td>24.6 (0.5, 48.7)*</td>
</tr>
<tr>
<td>Daily frequency of aspirin</td>
<td>0.92 (0.49)</td>
<td>0.62 (0.51)</td>
<td>0.3 (−0.1, 0.7)</td>
</tr>
</tbody>
</table>

*p < .05; **p < .001.
Note. MMSE, Mini Mental State Exam; BMQ, Beliefs about Medication Questionnaire.
significant differences between groups on these measures. There were no differences with regard to social class (DEPCAT) or time since stroke. Also there were no differences between the groups with regard to cognitive or language ability (Frenchay, Rivermead, or MMSE), or amount of medication taken (Table 1). Twice as many patients in the low adherence group were living alone, but the qualitative analysis suggests that there this was not associated with poorer medication adherence (see ‘Support’ below). This is supported by the fact that, within the low adherence group, those living alone had significantly higher total MARS scores (i.e., reported better adherence) than those living with someone else \( M = 21.2 \ (SD = 0.7) \) versus \( M = 18.0 \ (SD = 3.2) \), mean difference = 3.2, 95% C.I. (0.2, 6.1)]. There were three significant differences between high and low adherers: high adherers had significantly higher perceived benefit (of their medication) scores, significantly lower concern scores on the BMQ, and significantly higher necessity minus concern scores on the BMQ than low adherers (Table 1).

Throughout the following results section from the qualitative analysis, quotations are identified as belonging to a specific patient from either the high adherer (H1, H2 etc.) or low adherer (L1, L2 etc.) group, including gender, that is, M (=male) or F (=female) and age (in years), for example, H5, F, 50 (female patient, aged 50 years, fifth patient from high adherer group). Figure 1 shows the themes from the qualitative analysis. Two core recurrent themes emerged from the data: ‘stability of medication routine’ and ‘beliefs about medication’.

**Stability of medication routine**

Stability of medication relates to the degree patients developed strategies to help make it easier to take their medication and the extent to which those strategies became a habituated part of their daily routine. There were two sub-themes: ‘remembering versus forgetting medication’ and ‘support’ (from both family and health professionals).

Almost all participants in the high adherence group recognized the importance of having a stable routine for taking their medication, and most had found a system that worked well for them. Taking their tablets was often spontaneously described as

![Figure 1. Core themes.](image-url)
Adherence to medication in stroke survivors

‘routine’, ‘natural’, or a ‘habit’ and was consistently cued to particular daily activities such as showering or eating meals.

‘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 . . .’ (H5, F, 50)

‘I give myself a routine . . . I have my aspirin in the morning, after breakfast, and then I take my Serc one at lunchtime . . . I take three in the evening, after my meal . . .’ (H10, F, 78)

‘When I’m having my breakfast I take my Aspirin and my Metformin together, so that is that routine. And then at teatime I just have it (Metformin) with my meal . . .’ (H3, M, 55)

Some low adherers also acknowledged the importance of a routine in helping to take their medication, and, like high adherers, a few did tie them in with specific daily activities.

‘I always put them out at night. I’ve got a wee jug, and I put them out at night and then I take them after I’ve had a bit of toast and that.’ (L5, F, 49)

‘I thought, ‘Oh, that’s gonna be monotonous’, but it’s just something like brushing your teeth in the morning, you just get used to it. It’s an automatic thing to do now.’ (L3, M, 50)

However, whilst almost all low adherers described the times of day at which they aimed to take their medication, many were vague about exact timings.

‘Sort of about nine o’clock in the morning.’ (L3, M, 50)

‘Well, it can range between six and eight o’clock in the morning.’ (L9, M, 88)

‘I was supposed to get up and take it . . . but it would always be at random times.’ (L11, M, 22)

In addition, many low adherers did not view their medication regime as a formal routine, few spontaneously described it as a habit, and most did not link these times in to other cues such as mealtimes.

Interviewer: Do you have a set routine?

‘No, I just take them in the morning. My morning tablets in the morning, then at night time, the night ones.’ (L13, F, 62)

Some low adherers also reported intentionally varying the time at which they took their medication.

‘Well, not always the same time. I still manage to get out a lot, you know, so sometimes I take it when I come back in the afternoon, or most times, I take it in the morning.’ (L10, F, 78)

‘Any time, but I usually take it at night time.’ (L1, M, 78)

Even those low adherers with a fairly set routine appeared less successful at sticking to it than high adherers, which in some cases seemed to arise from difficulty in dealing with distractions.

‘Well, as long as I’ve got the box there, I’m fine, unless like today, I’ve been out and that and I sort of change it.’ (L2, F, 58)

‘. . . and the worst thing is when you put the television on to watch something, you know. You forget.’ (L10, F, 78)
Remembering versus forgetting medication

The first sub-theme of ‘stability of medication routine’ was remembering versus forgetting. This represents the degree to which patients reported that they remembered (or forgot) to take their tablets.

Many high adherers reported they found it easy to remember to take their tablets and/or that they rarely forgot. Frequently, this seemed to be a consequence of their establishing a regular routine for taking medicine (above), but some used additional cues or aids to help them remember to take their tablets, such as setting out the medication in a recognized place, which provided a visual reminder.

‘Well, I remember quite well actually... because I’ve got myself into a kind of routine.’ (H5, F, 50)

‘I just keep them in my cupboard above the kettle... well you open it to get the tea bags and you see all the pills literally in front of your eyes.’ (H13, F, 64)

‘No, (never forgets), on my wee table there, the wee round one, everything is all laid out, just like a Philadelphia lawyer!’ (H7, M, 83)

In contrast, low adherers were more likely to report forgetting to take their medication. For some, this forgetting seemed due to memory problems or the lack of a reminder, whilst for others it was down to the lack of a fixed routine, especially when other activities interfered with the time of day at which tablets were taken.

‘But, sometimes we do forget. It’s not everyday that we take it. We try to, you know.’ (L9, M, 88)

‘It was always to do with if I was going out or if I woke up late it just depends where the aspirin was. If I just never saw it then I would just forget to take it.’ (L11, M, 22)

‘But there is occasional times that I miss it out. Maybe if I’m away and I’m not back till later in the evening.’ (L10, F, 78)

In addition, interruptions to normal lifestyle seemed to present particular difficulties for low adherers.

‘Well, I spend half my life in England so I suppose it changes then. I just took them whenever I’ve got the time to take them.’ (L6, M, 45)

‘... I travel quite a bit and stay overnight and talk at conferences, so I can’t always use that strategy. This is where it is a nuisance.’ (L8, F, 59)

In contrast, many high adherers adopted additional strategies for coping with lifestyle interruptions, either to ensure they did not forget their medication, or to compensate for memory lapses once they did occur.

‘... we were away at an hotel and I forgot to slip Metformin into my jacket pocket which is what I normally do... and I realised crikey that I’d forgotten to take my tablets so I took it there and then.’ (H4, M, 55)

‘If I go out in the evening, I make sure I’ve got my pills in my pill box, ready to be taken.’ (H10, F, 78)

‘... 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 small Aspirins, so I just halved the big Aspirins ...’ (H6, M, 58)
In summary, it appeared that, although both high and low adherers recognized the importance of having a regular routine for taking their tablets, high adherers tied this in with daily activities, use cues as aids to remembering their tablets, and adopted strategies to help them to cope with lifestyle interruptions, which all led to them rarely forgetting their medication. In contrast, low adherers were less consistent over the timings of their doses, were less likely to use cues for remembering, and often allowed lifestyle interruptions to interfere with their medication regime, with the result that they were more likely to forget to take their tablets.

Support
A second sub-theme of ‘stability of medication routine’ was support which aided patients in taking their medication. Patients described help and advice from both family members and health practitioners.

Both high and low adherers used family support as a scaffold to help maintain a stable medication routine. However, fewer high adherers \((n = 3)\) than low adherers \((n = 6)\) reported receiving direct help from family members in remembering to take their tablets, suggesting that lack of available social support was not a major factor in patients forgetting their medication. In addition, the type of support seemed to differ. Whilst relatives of high adherers tended to give support or practical aids to help the patient remember to take their tablets themselves, low adherers seemed to be more reliant on their relatives to give them their tablets, and so they became dependent on their relative’s availability or capacity to remember.

‘He’s quite organised now. He made quite a mess of it in the beginning, but we’ve got him organised now.’ (Relative of H9, M, 85)

‘Oh, yes, well I . . . my sister, she’s got everything well organised (for me) on my wee meal table.’ (H7, M, 83)

‘No, my son was away. He always makes sure I get my prescriptions and I forgot.’ (L6, M, 45)

‘I bring them out every morning . . . and put them in front of him. I couldn’t trust him to take them himself . . . . (although) I do forget sometimes.’ (Relative of L7, M, 80)

High adherers tended to have positive views of health professionals and the advice they gave about medication, and often used them as a source of practical help or reassurance.

‘They (the doctors) were very kind. They were very thorough.’ (H4, M, 55)

‘. . . 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.’ (H2, F, 58)

‘Yeah, which (a discussion with GP about side-effects) kinda reassured me cause you do read lots of different things in the papers, don’t you?’ (H5, F, 50)

As a consequence, most high adherers were happy to follow their doctors’ instructions regarding taking their medication, even if the medication was giving them difficulties.
Julie A. Chambers et al.

‘... 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.’ (H4, M, 55)

‘I didn’t enquire about it (a possible side-effect) anyway, I was told to take them and I just persisted.’ (H1, M, 77)

In contrast, low adherers generally had a less favourable view of health professionals’ advice than high adherers, often reporting mixed or confusing messages.

‘I don’t understand why I’m taking them. Some doctors have told me I shouldnae be taking them.’ (L6, M, 45)

‘But they never actually tell you what they are for. ... But you see half the time, you know, the doctor probably doesn’t know exactly what they’re for.’ (L7, M, 80)

Some low adherers went as far as to say that there was a lack of information and support from their doctors or that their doctor had failed to answer their questions or address their concerns.

‘I’ve never really had the results (of the hospital tests). Nobody’s ever bothered to tell me.’ (L9, M, 88)

‘Yeah, but he never reassured me and said, “Well, look, this is where this tablet is going or that is where that is.” I was still left in the dark.’ (L13, F, 62)

However, this was often compounded by the low adherers themselves, many of whom were reluctant to seek out support or information from their doctor.

‘I don’t wanna keep running to the doctor, I wanna go only when it’s really necessary.’ (L13, F, 62)

Interviewer: Have you asked the doctor if there is anything else you can take?
‘No, I’ve never thought of asking the doctor.’ (L2, F, 58)
‘I should have really made an appointment to go and see her (GP). I haven’t seen her since this happened 14 months ago.’ (L4, M, 55)

Perhaps because of this, quite a few low adherers also reported stopping their medication without consulting their doctor.

Interviewer: Did you speak to your GP about stopping it (the Simvastatin) first?
‘I didn’t actually, no I didn’t.’ (L4, M, 55)

High adherers, therefore, were willing to seek practical help and advice from health professionals, which seemed to provide reassurance and help convince them to take their medication as prescribed. In contrast, for low adherers, a perceived lack of information and support from health professionals and a disinclination to seek further advice may have contributed towards their poor adherence to medication.

Beliefs about medication and treatment
The second core recurrent theme that emerged was patients’ ‘beliefs about medication and treatment’.

As well as many high adherers reporting unquestioning trust in their health professionals, they also expressed confidence in the medicine itself.
‘I feel that whatever the doctor prescribes, they know what they are doing, and talking about. . . . I’ve got trust in the doctor.’ (H10, F, 78)

‘I have faith in the tablets.’ (H7, M, 80)

Even those who were less certain about the medication or experienced side effects tended to believe it would do them more good than harm, or that the doctor must have prescribed it for a good reason.

‘I was a bit worried, yes. Cause somebody said, “Oh, they’re not a good thing to be taking”, but I don’t feel they’ve done me any harm and at least I haven’t had a major stroke.’ (H12, F, 81)

‘Well, if the doctor’s given me something and he’s given me a time factor in which to take it, I’ll do it.’ (H1, M, 77)

In contrast, many low adherers seemed to have firm, often negative or erroneous, ideas about their illness or medication, and often questioned the necessity of taking it. Because of this, they often reported intentionally missing their medication or stopping their medication altogether, even if this was contrary to their doctors’ instructions.

‘I don’t take it (Simvastatin) all the time, I take it every third day.’ Interviewer: Why? ‘Because I thought it was silly taking them when I’ve got the other ones. They’re all counteracting one another. I told the doctor.’ (L1, M, 78)

‘Sometimes when my leg’s sore, I maybe take two Paracetamols in the morning . . . then I wouldnae take my Aspirin.’ (L10, F, 78)

In addition, because they did not feel any different when taking their medication, many low adherers believed their medication either was not doing them any good or was not having the desired effect, and this was also given as a reason for stopping.

‘I know what they’re for but I dinnae feel any different, you know.’ (L2, F, 58)

‘I didn’t think at first when I was taking them that they were doing me any good. And I did stop taking them.’ (L13, F, 62)

‘. . . in the event it didn’t change the cholesterol level at all over a period of three or four months so eh . . . . I felt, well it’s not really doing anything, I don’t have a diet of a fatty nature at all, so I just stopped taking it basically.’ (L4, M, 55)

Some low adherers also reported bad side effects of their medication. However, unlike high adherers experiencing side effects, who tended to persist with their medication or sought an alternative medicine from their general practitioner (GP), patients in the low adherence group were more likely to alter their dosage or stop taking their tablets altogether to counteract any negative reactions.

‘But when I’m having three I still get the reflux, so I just take two (now).’ (L2, F, 58)

‘. . . but other tablets that I was on, eh, it makes me a wee bit dozy. So, I stopped taking those tablets.’ (L5, F, 49)
Consequences

The first sub-theme of ‘beliefs about medication’ that emerged, classified as ‘consequences’, represented patients’ concerns about what would happen to them if they failed to take their medication as prescribed.

When asked, most high adherers either attributed quite severe consequences to both short- and long-term non-adherence of medication or, at the very least, thought it would increase their risk of stroke.

‘I think everything would be knocked to hell. And that’s putting it mildly.’ (H13, F, 64)

‘Well, if I missed out the Aspirin then it would cause my blood to go thicker and then it would cause a stroke.’ (H2, F, 58)

‘I think the chances would be greater, of having another stroke.’ (H5, F, 50)

For high adherers, these concerns over consequences of not taking their medicine therefore appeared to be a major motivation for continuing to take their tablets. This led them to accept any negative consequences (such as side effects) of taking the medication or concerns about their medication (such as long-term consequences), as being more than offset by the gains made. For some, this motivation overrode their preference to not take any medication.

‘Well, obviously if it helps then I’m quite happy to take them because I don’t want another one (stroke) . . . ’ (H2, F, 58)

‘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.’ (H4, M, 55)

‘I would love to wake up one and day and think, “Oh, I don’t need to take my medication”, but I don’t want to take that risk.’ (H11, M, 43)

However, it should also be noted that some high adherers reported major worries regarding taking their stroke medication:

‘I’m just terrified that I’m going to be asked to take more medication, cause I’m on quite a cocktail.’ (H4, M, 55)

‘Yeah, it could be quite scary sometimes, especially when you come to the one, “Oh, I’m taking that one”, you know what I mean.’ (H5, F, 50)

For high adherers, however, these concerns did not seem to negatively affect their adherence rate. It appears, therefore, that having trust in both the health professionals and their medication, and a definite belief or worry that there would be negative consequences if they missed the medicine, has the resultant consequence of motivating these patients to strongly adhere to their medication.

Low adherers expressed a range of views regarding the potential effects of missing medication. Whilst some patients in this group mirrored high adherers in indicating that they would be very worried about missing their medicine, many low adherers appeared somewhat un-concerned, unsure or had not thought about the consequences of not taking their tablets.

‘If you did miss out your tablets then you would be in trouble.’ (L1, M, 78)

‘I dread to think. I’d probably have a stroke.’ (L3, M, 50)
Adherence to medication in stroke survivors

‘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.’ (L8, F, 59)

‘I don’t really know. Well, I don’t know. I honestly don’t know.’ (L6, M, 45)

‘Oh, I don’t know. I don’t think it (missing medication) would do me any harm at all.’ (L9, M, 88)

Low adherers who said they did not see any harm in not taking their medication may have a lack of understanding of what their medication is for and/or be confused as to the reasons why they have been given it to take. Alternatively, it could be that these patients have simply given little thought to the consequences of stopping their tablets, or, as mentioned earlier, attributed little benefit to taking the medication in the first place.

‘I’ve never thought about it really. I haven’t a clue.’ (L2, F, 58)

‘... I think I need to feel it’s doing some purpose and I wasn’t sure it was doing anything.’ (L4, M, 55)

Dislike of medication

Patients from both the high and low adherence groups reported that they disliked taking their medication or that they would prefer not to have to take it.

‘I wouldn’ae take them of it were up to me ... but I know I’ve got to take them now.’ (H3, M, 50)

‘I don’t like taking them.’ (L9, M, 88)

However, as well as saying that they had no option but to take it, high adherers were pragmatic about the need to persist.

‘The fact that I think it may be doing some good, I’ll persevere with it.’ (H1, M, 77)

‘I’m following the advice that I’ve been given, so there’s no point in fretting about it.’ (H4, M, 55)

In contrast, whilst some low adherers also accepted it was necessary, many reported a strong aversion to taking their medication and bemoaned the effects on their lifestyle. These patients, in particular, tended to report very poor adherence.

‘I’m alright, but it annoys me when I’ve got to go away with my work and I’ve got to remember to take this tablet with me ... And I think, “Well I’ve just got to do it.”’ (L8, F, 59)

‘Well, the bad points is that I have to take these tablets, and they restrict my life.’ (L6, M, 45)

Patients’ knowledge

The third and final sub-theme of ‘beliefs about medication’ is ‘patients’ knowledge’.

Almost half of the high adherers seemed to have a good understanding of their illness and the reasons they did been given their medication, and this often reinforced the importance of taking their tablets.

‘Well, obviously the one that will lower my cholesterol, which wasn’t particularly high, but obviously it lowers it a bit more to avoid the stroke.’ (H2, F, 58)
‘... my cholesterol . . . they said at the hospital was 4.7 which was quite good, but they wanted to get it down again . . . And that’s why I had the statins and I am still taking them.’
(H10, F, 78)

In contrast, many low adherers showed a lack of awareness of what their medication was and why they were taking it. Although a few did seem fairly well informed about at least some of their medicines, the majority clearly was not.

‘I have three pills, which I take in the morning, and I have Simvastatin, which I take before I go to bed, and I take a mild laxative cause I have got problems with constipation which I think is due to the high blood pressure medication.’ (L8, F, 59)

‘There’s a lot of them I don’t know what they’re for. I’ve just always had them.’ (L6, M, 45)

Hence, knowledge of medication was poor in this group, and low adherers often indicated that not only did they not know what they were taking but also they relied on the colour of the capsule to tell the difference between tablets.

‘There’s the wee white one I’ve to take. It’s like a Paracetamol. It’s got a P written on it, and I take two Paracetamol along with it. I reckon what it is, I dinnae ken what half the pills are.’ (L12, F, 81)

Low adherers also indicated confusion over the process of taking their medication, especially when they had to take a lot of different tablets.

‘It’s a lot of tablets. At one point I just felt, I felt as if I was dizzy with all these tablets.’ (L13, F, 62)

In summary, both high and low adherers had concerns about their medication, and both groups had some inaccurate beliefs as to the consequences of not taking it. However, whilst high adherers focused on the negative outcome of not taking their tablets, low adherers appeared more concerned with the bad effects of taking them. In high adherers, any concerns seem to be offset by the perceived benefit of their medication, which may be related to their apparent better knowledge of why they had been given it to take, coupled with trust in the medical profession. The poorer knowledge amongst low adherers may have contributed to an underestimation of the benefits and an overestimation of the negative effects of their tablets. In addition, their mistrust of both doctors and medicines, often compounded by their own reluctance to seek out advice and help, is likely to have increased their disinclination to take their tablets. We do not know whether the groups differ in their past experiences of taking medication or of the medical profession itself, which may have shaped these views. Nonetheless, increasing patients’ knowledge may assist in changing these beliefs.

Discussion

There is a dearth of literature on medication adherence in stroke patients. Our results provide an evidence base upon which to base discussion and tentative conclusions.

The results of both thematic analysis groups (high and low adherers) in this study, indicated that the two key variables that were strongly associated with adherence in stroke survivors are the stability of a patient’s medication routine and patients’ beliefs and perceptions concerning their medication and/or treatment.

Patients who demonstrated high adherence had established a stable medication routine, making it an essential part of their daily lives, and used cues as reminders, which made it relatively easy for them to remember to take their tablets. They also
adopted coping strategies for lifestyle interruptions. Where necessary, they sought out support and advice from both family and health professionals, and expressed trust in their doctors. Many had a good understanding of the reasons for taking their medication, and many appeared to hold a pragmatic view of the consequences and risks of not taking their medication. In particular, their belief that there could be negative or even serious consequences to non-adherence acted as a strong motivation to take their medication. These factors all helped them to reach optimal adherence levels to their medication.

In contrast, those showing poor adherence often reported forgetting to take their medication, in many cases because they had failed to establish a consistent medication routine. Generally low adherers were less concerned about the consequences of missing or even stopping their medication. Some doubted the benefits they were getting, and many expressed an active dislike of their medication or medication in general and complained that it interfered with their lifestyle. Although knowledge of medication was patchy in this group, they were reluctant to seek advice from health professionals and often felt doctors gave insufficient information or confusing messages, which added to their lack of understanding of the benefits of taking their tablets. Family support was generally good, but low adherers often placed an overreliance on this help, and so interruptions to this support also led to forgetting medication. For low adherers, therefore, the lack of a stable medication routine, negative views about medication, and a meagre knowledge of their need for medication, compounded by a perceived lack of information and support from health professionals all appeared to contribute to poorer adherence.

Medication adherence amongst stroke survivors is a vital component in the prevention of recurrent strokes and other cardiovascular events. The results from our interview data, which indicate that patients both forget their medication, and actively alter the dose or stop taking their tablets, suggest that there is scope to increase adherence to greater levels with the aim of preventing further strokes and cardiovascular events.

The present study found that both intentional and non-intentional non-adherence are important in explaining variance in medication adherence in stroke patients. Many patients in this study reporting forgetting, or non-intentional non-adherence, particularly if they had failed to establish a regular routine. In addition, intentional non-adherence emerged as a strong theme amongst low adherers in our study, many of whom reported changing doses or stopping medication altogether. This seemed to be motivated by low adherers frequently questioning the benefits whilst reporting many concerns about their medication, the latter of which has been highlighted as a major reason for non-adherence in previous qualitative research (Pound et al., 2005). In contrast, in the current study, high adherers clearly felt that the benefits of taking their medication far outweighed any possible negative effects. The quantitative results from these participants support this difference, that is, low adherers had significantly higher concerns scores on the BMQ and significantly lower perceived benefit (of medication) scores than high adherers. The degree to which necessity outweighed concerns (necessity minus concern scores) on the BMQ was also significantly higher for high adherers than low adherers.

**Limitations**

The sample size of the current study was dictated by the number of people reporting low adherence to their medication (MARS score ≤ 22) and was not as a consequence of saturation of themes being reached. It is therefore possible that themes relating to medication adherence in stroke patients have been missed. Nonetheless, during the
second independent analysis of the transcribed interviews, saturation of coding for both low and high adherers was reached before the last patients were analysed, that is, no new themes or sub-themes were added after patient number 10 (high adherers) and 8 (low adherers).

Conclusion
Our findings suggest that an intervention aimed at eliciting and challenging low adherers’ specific concerns regarding the negative consequences versus the benefits of taking their medication, and increasing patients’ knowledge, might be effective in addressing intentional non-adherence. We also propose that unintentional non-adherence could be addressed by helping patients establish a stable and automatic medication-taking regime, for example via an implementation intentions approach, which has been shown to be effective at reducing forgetting and in improving medication adherence (Webb & Sheeran, 2006). Implementation intentions remove the burden of having to think about and remember when to act by using environmental cues (such as mealtimes, or keeping tablets on view) to trigger the desired behaviour, an approach that appears to have been adopted spontaneously by high adherers in the current study.

Based on the current findings, we are now embarking on a pilot study to evaluate the feasibility of a brief intervention to address both intentional and non-intentional adherence to medication in stroke patients exhibiting sub-optimal adherence (O’Carroll, Dennis, Johnston, & Sudlow, 2010). Our aim is to test whether medication routines and beliefs are changeable, and to what extent any changes in illness and medication beliefs and/or reductions in forgetting will contribute to improved adherence. If successful, this approach could prove a valuable tool to help maximize medication adherence, and hence patient benefits, in routine clinical practice.

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References


