Young adults’ experience of stroke: a qualitative review of the literature

Maggie Lawrence

Abstract

Stroke is a life-threatening event that has a devastating impact on young adults and their families. The author conducted a systematic review of the qualitative literature to explore the experience of stroke from the perspective of young adults. Four primary research ‘papers’ were analyzed using the Qualitative Assessment and Review Instrument; 60 findings were extracted from the papers and merged into 13 categories, from which three synthesized findings were developed — disorientation, disrupted sense of self, and roles and relationships. Many of the effects of stroke are ‘invisible’ but have significant impact on social participation, including the ability to return to work and to enjoy an active social life. Young adults feel the same and yet different following stroke, which may have a profound effect on relationships. Effective communication between patients, families and health professionals is crucial to all aspects of recovery.

Key words: ■ ‘Invisible’ effects of stroke ■ Qualitative review ■ Relationships ■ Stroke ■ Synthesized findings ■ Young adults

Method

Search strategy

Inclusion and exclusion criteria were determined (see Table 1) and appropriate electronic bibliographic databases identified (i.e. BNI, CINAHL, MEDLINE and PsycINFO). Structured searches were designed based on the keywords ‘stroke’ and ‘young’, and their synonyms. A feature of the ‘young adult’ stroke research is the lack of consensus regarding the definition of the term ‘young’. Thus to ensure all relevant papers were included, studies with participants aged between 18–65 years were retrieved.

Analysis

The review data were managed using the internet-based Qualitative Assessment and Review Instrument (QARI), which may be accessed free of charge from www.joannabriggs.edu.au. QARI was selected for use in this review as it provides a framework that enables the reviewer to develop theoretical

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Accepted for publication: January 2010
concepts, which describe the phenomenon under scrutiny, rather than simply presenting a narrative description of the findings reported in the primary research papers included in the review (McInnes and Wimpenny, 2008).

**Results**

Searches of the four databases were conducted in 2008, resulting in the identification of 196 bibliographic records. Their abstracts were screened using the inclusion and exclusion criteria (Table 1). Three papers met the review criteria: Bendz (2003); Röding et al (2003); and Banks and Pearson (2004). A doctoral study (Immenschuh, 2003) known to the reviewer was also included. In all, four primary research ‘papers’ were included in the review.

**Table 1. Inclusion and exclusion criteria used in the review process**

<table>
<thead>
<tr>
<th>Inclusion criteria</th>
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<tbody>
<tr>
<td>Study population</td>
<td>Stroke Young adults (aged 18–65 years)</td>
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<td></td>
<td>Non-stroke populations Children (aged 0–18 years) Older adults (aged &gt;65 years)</td>
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<tr>
<td>Study design</td>
<td>Qualitative studies</td>
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<td>Case studies</td>
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<td>Personal accounts</td>
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<td>Quantitative studies</td>
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**Box 1. Review paper A (Banks and Pearson, 2004): bibliographic details, aim, study design, sample characteristics and key findings**

Review paper A

Aim and study design
To explore the ways in which stroke impacts differently on the YASs involved and their partners (FMs) Methodology: qualitative
Data collection tools: interviews incorporating the Lifegrid method (Blane, 1996)
Data collection time points: 3–6 months then 6–9 months post-stroke

Sample characteristics
Population: community-dwelling YASs and FMs
Sample size: 38 YASs and 36 FMs
Gender: YASs, 22 male and 16 female; FMs, not stated
Age: YASs range from 20–49 years (mean = 44.0 years); FMs, not stated
Employment: not stated
Time post-stroke: 3–6 months (at recruitment)
Stroke type: not stated
Functional recovery: not stated
Aphasia: not stated
Cognitive impairments: not stated

Key findings
Between 12–15 months post-discharge from hospital some participants described altered roles, additional responsibilities, altered relationships and communication problems. Few couples had been offered counselling or psychological support

FM=family member; YAS=young adult who has had a stroke

**Box 2. Review paper B (Bendz, 2003): bibliographic details, aim, study design, sample characteristics and key findings**

Review paper B

Aim and study design
To explore perceptions of stroke rehabilitation from the perspective of health professionals and YASs Methodology: phenomenography
Data collection tools: healthcare professionals’ records, qualitative interviews (YASs)
Data collection time points: 3, 6 and 12 months post-stroke

Sample characteristics
Population: patients within a stroke unit
Sample size: 15
Gender: 9 male and 6 female
Age: not stated
Employment: 8 unemployed at time of stroke
Time post-stroke: 3 months (at recruitment)
Stroke type: not stated
Functional recovery: 13 independent on discharge (activities of daily living index)
Aphasia: able to ‘understand and express themselves verbally’
Cognitive impairments: not stated

Key findings
Healthcare professionals’ perspective was ‘mainly biomedical’ and focused on functional rehabilitation; the patients’ perspective included biomedical, social and psychological aspects. Young adults regarded function as a means to an end; their focus was on regaining pre-stroke (social) normality or adapting to altered circumstances. No difference was discerned between the rehabilitation goals of the patients and the healthcare professionals; only the perspective differed

YAS=young adult who has had a stroke
Bibliographic details of the papers are presented in Boxes 1–4, along with details of each study aim and design, the characteristics of the sample and a summary of the key findings.

Qualitative findings (n=60) were extracted from the review papers, entered into QARI and then grouped into 13 categories (see Box 5). Categories with similar meanings were then merged to create three ‘synthesized findings’ (see Box 6):

- Disorientation
- Disrupted sense of self
- Roles and relationships.

These synthesized findings, which describe the experience of stroke from the perspective of young adults, are presented in detail below. The synthesized findings, or themes, are illustrated with references and quotations from the primary research papers, which are identified by the relevant letter (A–D; see Boxes 1–4) and the appropriate page number.

**Disorientation**

**Sudden onset**

Stroke is a traumatic event. For many, it is unexpected, coming ‘out of the blue’ (C, p.107) and hitting without warning (A, p.419; B, p.217). For others the onset of stroke is gradual, with vague symptoms being experienced over the course of several days, which may result in a delay in seeking medical assistance (A, p.419).

**Knowing the cause/fear of recurrence**

Young adults want to know what has caused their stroke.
### Box 5. Findings extracted from the four review papers and allocation to 13 categories.
The review papers are identified by a code letter: A=Banks and Pearson (2004); B=Bendz (2003); C=Immenschuh (2003); D=Röding et al (2003)

<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
<th>Qualitative Findings</th>
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<tbody>
<tr>
<td>1. Sudden onset</td>
<td>Onset may be sudden or insidious. With hindsight, many YASs described vague symptoms over several days; help seeking was delayed.</td>
<td>The stroke event (A); stroke is a disruption — sudden onset (C); no warning (B); stroke is a traumatic event (A); seeking assistance (A)</td>
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<tr>
<td>2. Knowing the cause</td>
<td>YASs need to be able to identify the cause of their stroke. A desire to know what had caused the stroke (A); being in control — cause of stroke (C); uncertainty and fear — lack of control (C); need for information — cause of stroke (B)</td>
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<td>3. Fear of recurrence</td>
<td>Fear of recurrence/another stroke might hit (B); lack of knowledge about risk factors (B); stroke as disruption — avoiding stressful situations (C)</td>
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<td>4. Recovery</td>
<td>YASs focus on physiotherapy as the means of recovery. Back to normality — rapid recovery (C); physiotherapy is the means of recovery (B); coping with change — difficulty accessing services (A)</td>
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<tr>
<td>5. Effects of stroke</td>
<td>YASs no longer feel in control of their own bodies. They are aware of physical, emotional and cognitive changes. They fear that these changes will affect their ability to cope with life.</td>
<td>Cannot control your body (B); coping with change — emotional and affective changes (A); coping with change — aphasia (A); coping with change — cognitive changes (A); stroke as disruption — cognitive effects (C); loss of control of life — cognitive effects (B); coping with change — fatigue (A); fatigue (D); loss of control of life — fatigue (B); stroke as disruption — fatigue (C); coping with change (B)</td>
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<tr>
<td>6. Reappraisal</td>
<td>Stroke causes YASs to be aware of their own mortality. They reappraise and re-evaluate life. They understand life in a different way and have new priorities. Stroke as disruption — mortality (C); stroke as disruption — being thrown off balance (C); stroke as disruption — life before and after stroke (C); new orientation (D); stroke is a turning point — new appreciation of life (C); new orientation — gratitude (D); gender-related issues — new appreciation of family (D); gender-related issues — financial security (D); life situation has changed (B)</td>
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<tr>
<td>7. Difference and sameness</td>
<td>YASs feel the same and yet ‘different’</td>
<td>Disruption of sense of self (C); sameness and difference (C)</td>
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<tr>
<td>8. Return to normality</td>
<td>YASs aim to regain normality and to consign stroke to the past. Disruption of normality — regaining normality (C); regaining normality — social position (B); being in control — aim to make stroke a ‘closed chapter’ (C)</td>
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<tr>
<td>9. Being in hospital</td>
<td>The young adults’ experiences of being in hospital and being a patient. Inpatient hospital stay (A); uncertainty and fear — negative experience of hospital (C); being in control — treatment (C); treatment (A); information needs — coping with crisis (A); lack of information (D); lack of active involvement (D); insufficient rehabilitation — no individualized approach (D); specific needs and circumstances (A); lack of age-adapted rehabilitation (D); uncertainty and fear — not an old person (C)</td>
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<tr>
<td>10. Transitions</td>
<td>Returning home — anticipation and reality</td>
<td>Coming home (A)</td>
</tr>
<tr>
<td>11. Family relationships</td>
<td>Altered roles and relationships within the family. Relationships in transition (A); impact on relationships (A); concerned about being a burden (A); coping with change — frustration (A)</td>
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<tr>
<td>12. Social participation</td>
<td>Altered roles and relationships at work and socially. Stigma (C); outside and invisible — cognitive changes (D)</td>
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<tr>
<td>13. Talking to young adults</td>
<td>YASs want to talk to other YASs. The need to talk — other people to identify with (C); need to talk to other young adults (A)</td>
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**YAS**—young adult who has had a stroke
Stroke is unexpected. Young adults want to know what caused their stroke and how they can prevent recurrence. They focus on recovery and returning to normal. They focus on rehabilitation therapies as a means of recovery and feel that they do not get enough therapy. They experience physical, cognitive and affective effects of stroke.

The effects of stroke:

Following stroke, young adults experience physical effects, which include an inability to control limbs and muscles and altered bodily sensations (B, p.218). They also experienced cognitive effects, such as problems with memory, concentration and language:

‘I’m still having difficulty expressing myself and [in] my writing...I get my words all mixed up...’

(A, p.423).

Recovery:

Young adults were frustrated if clinicians were unable to give them a clear indication of expected recovery:

‘Well if you sum it up, if you summarize it...I was an adult and a clear-headed man so they could have said it straight out, that this will mean years of rehabilitation’ (D, p.870).

However, for many in the short-term there is a sense of relief regarding recovery and the subsequent return to ‘normal’ (C, p.225; B, p.217). In hospital, young adults focus on physiotherapy as a means of recovery (B, p.219), although both in hospital and at home they feel that their recovery is hampered by the lack of adequate access to therapy (D, p.871; A, p.423).

The fear of recurrence persists over time and is coupled with the fear that another stroke might be worse; the uncertainty about whether a stroke is to happen again persists (C, p.135).

Some young adults are unable to identify the risk factors for stroke (B, p.219). However, they describe using strategies to prevent recurrence that focus on the avoidance of stressful situations, such as work and holidaying abroad (B, p.219; C, p.147).
**Disrupted sense of self**

*Reappraisal*

Stroke is a life-threatening event that causes young adults to reflect on their own mortality (B, p.218). It represents a turning point in their lives (C, p.117); life is perceived as life before stroke and life after stroke, and all their plans for the future are affected (B, p.217; C, p.120). Stroke causes young adults to reflect on their experience, resulting in new insights regarding the value and meaning of life. Following stroke, there is a tendency to live life one day at a time (C, p.130), and a new appreciation of the ‘gift of life’ (C, pp.118–19). Although young adults experience many effects of stroke, they are grateful that their stroke was not worse than it was and feel lucky in comparison with others:

> ‘I was lucky because I have seen others who have suffered from this and what happened to them’ (D, p.869).

*Difference/sameness*

Stroke disrupts young adults’ sense of self (A, p.419; C, p.121). They want to be the same as they were before their stroke:

> ‘I want to get back to my usual self…the one I used to be’ (B, p.220).

However, following stroke young adults perceive themselves as different. This ambiguous response is a cause of stress and tension, particularly with regard to work as they try to balance the demands of work with attempts to ‘pass as normal’ (C, p.193).

Stroke causes young adults to question who they were before their stroke, who they are now and who they want to be in the future (C, pp.107–8). Following stroke they re-evaluate and reprioritize their lives (C, p.242; D, p.869); for example, some reappraise their role as parents (D, p.870) or grandparents:

> ‘I want to do different things now. I want to live and I want to spend more time with the grandchildren. I want to enjoy the time I have left. All my life I have concentrated on work. I don’t want to do that any longer’ (B, p.220).

*Return to normality*

Six months after stroke, there is a perception that recovery has slowed and returning to ‘normal’ no longer seems inevitable (C, p.111). There is an increasing sense of not being in control of their bodies and their lives, and young adults combat this by focusing on the present with many aiming to return to employment as quickly as possible:

> ‘I’m looking forward to being able to go back to work again…that is very important. Actually, just as important as eating and drinking’ (C, p.225).

**Consigning stroke to the past**

The first anniversary of the stroke event is an important marker of recovery and of returning to the ‘old self’; many young adults try to put stroke behind them. It is consigned to the past by avoiding stressful situations and by explaining any long-term effects of stroke as the effects of ageing:

> ‘I forget things…I don’t know whether that’s only the ageing process…now it is the case that I have to write down more things’ (C, p.184).

The young adults looked to the future and aimed to remain in the world of the healthy (C, p.255). However, many young adults acknowledged that their old self had changed because of new insights gained as a result of their illness experience:

> ‘It’s over and done with…I’m proud of how I dealt with it…but it’s past, finished’ (C, p.174).

Some young adults chose to retain their awareness of stroke because they wanted to maintain the positive changes they had made to their lives (C, p.216).

**Roles and relationships**

*Being in hospital*

On admission to hospital, young adults hand over responsibility and become ‘patients’ (A, p.420). They are happy for others to make decisions on their behalf (D, p.870). However, they feel that health professionals do not understand their everyday needs, problems and goals (D, p.871). They are frustrated because they feel as if they are passive recipients of rehabilitation therapy. They feel that therapists do not actively involve them in their own rehabilitation and, consequently, they do not understand the purpose of specific rehabilitation activities (A, p.420):

> ‘I was referred to the rehabilitation ward…but I really did not understand what I was supposed to do there’ (D, p.870).

Many young adults remember their hospital stay positively (A, p.421). However, for some it was a negative experience that caused anxiety, shame and uncertainty. In particular, the association of stroke with old age was frightening and distressing (C, p.258):

> ‘It was frightening in the hospital because they said “We’re going to take you up to the geriatric ward.” I tried to make a joke out of it, saying that I’m not a geriatric, but that was where everything was done’ (A, p.420).

However, staff did try to accommodate young adults’ needs, for example by giving them single rooms and by being flexible regarding visiting times (A, p.421).

*Transitions*

Following stroke, young adults find transitions difficult, including transferring from an acute stroke unit to a rehabilitation unit, being discharged home and returning to work (C, p.197). For many, returning home is a transition that is eagerly anticipated and one that signals a return to ‘normal’. Often however, the reality is very different:

> ‘When you’re in hospital, you don’t really think about how your life is going to be when you leave…You think that you’ll just carry on as before, but you don’t. You get home and that’s when the trauma starts’ (A, p.422).
Family relationships
Young adults are afraid of being a ‘burden’ to family members but they are unable to communicate their feelings effectively (A, p.422). They are frustrated by the consequences of the limiting effects of stroke, such as fatigue, and the ambivalent state of sameness/difference that leads to feelings of frustration, which are often vented on other members of the family:

‘I quite often lose my head with [my husband]…he’s been quite patient with me but I don’t feel we talk enough…I don’t tell him what I’m really feeling’ (A, p.423).

Some young adults find that sexual relationships have changed and there is a sense of loss of closeness (A, pp.425–6). Some young adults feel that stroke contributes to the breakdown of marital relationships; they feel estranged from their partners who are unable to understand their illness experience (A, p.423). However, other young adults find that stroke has strengthened their relationship and brought them closer emotionally (A, p.423).

Social participation
With regard to participation in leisure and social activities, many young adults feel marginalized by the effects of stroke that limit their social activity and their ability to participate (C, p.172):

‘If I’m going to do something, I can only do it for a while and after that I get tired and my head sort of spins and if there are many things or many people around me then I get tired faster’ (D, p.868).

As many of the effects of stroke are ‘invisible’, young adults find that other people quickly forget that they have had a stroke and expect too much of them (C, p.121; D, p.871). Ambiguously, however, young adults also feel as if other people treat them differently, despite their attempts to ‘pass as normal’:

‘What hurts me most and sticks out for me is that…I do have the constant feeling of having to prove that you’re normal…people withdraw a little because they can’t deal with it’ (C, pp.192–3).

Talking to other young adults
While in hospital, young adults are likely to be treated in wards with older adults; however, the young adults feel that they would benefit from opportunities to talk to other young adults who, they feel, would be better able to understand their experiences (A, p.424; C, p.194):

‘I felt like there was no one that I could share my experiences with at the ward. I was only 38 years old and I had to be together with those who were 70–80 years’ (D, p.871).

Discussion
This qualitative review was undertaken to facilitate an understanding of the experience of stroke from the perspective of young adults. A minimum of two reviewers is recommended when conducting a systematic review (Petticrew and Roberts, 2006). However, only a small number of papers was involved and QARI software was used, which may have militated against the potential for bias associated with reviews conducted by a single reviewer.

Findings were extracted from four primary research papers and grouped into categories from which synthesized findings were developed to enable a theoretical description of young adults’ experiences of stroke. The synthesized findings, disorientation, disrupted sense of self, and roles and relationships, were used as headings under which to describe aspects of the young adults’ experiences.

Stroke hits suddenly, without warning, and young adults are disoriented by this shocking, life-threatening event and the effect it has on their bodies. Their previously taken-for-granted life is suddenly thrown into sharp focus as they become aware of the impact stroke has on their bodies and how they relate to others and to their environment (Svenaeus, 2000; Lawrence, 2009). Once the acute phase is over, young adults want to know what caused their stroke. Often, however, clinicians are unable to identify a causative factor (Leys et al, 2002). If a cause cannot be determined, young adults who commonly fear recurrence of stroke do not know what strategies to adopt that may prevent recurrence. This remains a worrying and problematic issue (Lawrence, 2009), which is further compounded by their lack of awareness regarding the risk factors for stroke (Bendz, 2003). This lack of knowledge regarding risk factors for stroke and recurrent stroke is common among the general population, including adults who have previously had a stroke (Yoon et al, 2001). It may be that the provision of secondary prevention interventions, which combine drug therapy with lifestyle advice and support, is a means by which young adults’ fear of recurrence may be addressed, as individuals would be empowered to make lifestyle changes that may help prevent the recurrence of stroke (Lawrence et al, 2009a).

Young adults experience physical, cognitive and affective effects of stroke and focus on rehabilitation as the principal means of recovery. However, they feel that their recovery is hampered as they do not get enough therapy, a finding echoed by Low et al (2003) in their survey of members of the Stroke Association’s young adult groups. They found that young adults had many unmet needs, including needs for a range of rehabilitation therapies and, in particular, for long-term therapy provision. However, it is often the cognitive and psychological effects of stroke (i.e. the invisible effects of stroke) that constitute a barrier to taking up life as it was before stroke, including the individual’s ability to resume his/her former role within the family, at work and socially.

Stroke is a life-threatening event and as such causes individuals to re-evaluate their priorities in life and to change aspects of their life, such as altering their work/life balance and valuing family relationships (Secrest and Thomas, 1999; Mahrer-Imhof et al, 2007). However, work remains an important factor in many young adults’ lives, as has been described by Corr and Wilmers (2003) in their studies of young adults post-stroke, and they seek to return to employment as soon as possible.

Following stroke, young adults perceive that their relationships with others and their roles at home, at work and in their wider social networks have altered. There is a sense of being somehow different and that only other young adults can fully understand their experiences (Immenschuh, 2003). Relationships with family...
members in particular may be vulnerable to breakdown (Secrest, 2000), because of failures in effective communication (Banks and Pearson, 2004). For example, young adults often refrain from communicating their worries to their spouses/partners and close family members for fear of burdening them. Similarly, family members do not communicate their concerns for fear of adding to the young adult’s burden, and such communication failings may lead to feelings of resentment and of emotional distance (Banks and Pearson, 2004; Lawrence, 2009). In addition, chronic fatigue, which is frequently experienced by young adults, gives rise to feelings of frustration in the affected individual, which are vented on unwitting family members (Smith et al, 2004).

Conclusion
Stroke has a devastating impact on young adults and their families. It can affect motor, sensory, language, cognitive and social functioning. Many of its effects are invisible, but may have significant impact on relationships and wider social participation, including the ability to return to work and to enjoy an active social life.

Young adults should be referred to young adult support groups such as those provided by Chest, Heart and Stroke Scotland (www.chss.org.uk), Different Strokes (www.differentstrokes.co.uk) and the Stroke Association (www.stroke.org.uk).

Further research
Research regarding the effectiveness of interventions designed to address the lifestyle risk factors for recurrent stroke is required. A systematic review on this topic is currently in progress (Lawrence et al, 2009b). Research is also required to investigate aspects of stroke, such as living with the ‘invisible’ effects of stroke and the effect of fatigue on relationships and on social participation.

KEY POINTS

- Stroke has a devastating impact on young adults and their families.
- Young adults need to be clearly informed of the cause of their stroke, if this has been identified.
- Young adults fear having another stroke and want to know how to prevent recurrence. Information regarding lifestyle risk factors for recurrent stroke should be provided, along with appropriate referrals to specialist agencies, e.g. smoking cessation services.
- Young adults should be equipped with strategies to help them cope with the invisible effects of stroke, such as chronic fatigue, thus enabling them to return to work and to enjoy an active social life.
- Young adults should be actively engaged in the rehabilitation process to ensure that their individual needs and priorities are met. The rationale for engaging in specific rehabilitation tasks and activities should be clearly explained.
- Young adults should receive emotional and practical support during periods of transition. Effective communication between patients, families and health professionals is crucial to all aspects of recovery.

Acknowledgements
The reviewer gratefully acknowledges the Postgraduate Studentship awarded by the Chief Scientist Office, Scottish Executive for a programme of doctoral research that inspired the topic of this review. The reviewer would also like to acknowledge the systematic review training and support provided by the Scottish Centre for Evidence Based Care of Older People, a Collaborating Centre of the Joanna Briggs Institute (http://www.geal.ac.uk/jbienet/).


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British Journal of Nursing, 2010, Vol 19, No 4