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Striking a balance: The critical importance of sense-making and values-congruent partnerships between general practitioners and patients following stroke

Carolyn Ehrlich, Elizabeth Kendall, Tara Catalano

Abstract

Objective: People with a recent experience of stroke commonly rely on general practice for assistance to manage everyday consequences and associated disability. In this study, we were interested in qualitatively exploring how the relationship between these people and their general practitioners assisted daily self-management.

Methods: One hundred twenty-six participants were involved in five in-depth interviews over an 18-month period after discharge from an acute care setting. Data were thematically analyzed by two independent researchers.

Results: Three themes comprehensively accounted for the expectations participants had about their interactions with general practitioners. They were (1) the critical sense-making role of general practitioners, (2) the requirement for collaborative partnerships in which personhood was validated, and (3) the importance of confirming self-management actions.

Conclusion: To comprehensively assist people to adjust to living with the residual consequences of a recent stroke, general practitioners need to engage in collaborative, person-centered interactions.

Keywords: Person-centered care; self-management; general practice; cerebrovascular; partnership; recovery

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Introduction

Stroke is both an acute condition and a lifelong disease process with long-ranging social consequences [1, 2]. For many survivors, stroke is experienced as a fundamentally life-changing event that creates uncertainty and anxiety and requires continuous mastery of new skills [3–5]. However, developing a sense of mastery after stroke is challenging, because survivors are required to simultaneously live with a stroke-induced disability, deal with the

real potential of stroke recurrence, and manage a long-term recovery trajectory [6]. The permanence of many stroke sequelae means that adaptation and ongoing skill development requires coordinated multidisciplinary specialist rehabilitation, caregiver, patient, and family engagement, education, and goal-setting [1, 7]. Thus, it is common for many people who have sustained a stroke to require ongoing interactions with the medical system.



In Australia, general practice is both an entry point to other health care services within the medical system [8] and a place for ongoing coordination and management of chronic conditions. General practice is, therefore, ideally placed to facilitate ongoing stroke care. However, optimal chronic condition care requires a movement away from viewing patients as passive recipients of care toward engaging them in a collaborative system of care in which they are viewed as having genuine expertise [9–12]. In response, health care professionals are increasingly being required to develop partnerships with patients and support them to take an active role in managing their own condition (i.e. self-manage) [12–15].

A partnership approach is reliant on shared decision-making [14, 16–18], which is frequently described as the middle ground between paternalism and autonomy [11, 19]. However, genuine sharing of expertise and power in relationships between health professionals and patients is extremely difficult to achieve [9]. Although shared decision-making is advocated, physicians inherently have more power in these relationships, which impacts on the decision-making contribution of patients [20, 21].

In one Australian study, researchers identified that 58.6% of patients described positive long-term values-concordant partnerships with their general practitioners (GPs). However, 9.7% of patients preferred that their GP was in control of the decision-making process [22]. These patients were typically older than 65 years and did not believe they were responsible for their own health. In contrast, another study found that older patients attach more importance to shared decision-making than younger patients [23]. However, it was also found that involvement in decision-making about medical issues varied, and was significantly correlated with the importance placed on participation by patients.

Discrepancies in perceptions about participation in decision-making between GPs and their older patients are concerning, especially when self-management support and shared decision-making are recognized strategies for the successful management of chronic conditions [24, 25]. Our interest in perceptions about self-management support in the general practice setting was heightened when data from a larger study that we had conducted regarding the self-management processes used by older people who had recently experienced stroke

indicated that their relationships with their GPs influenced their self-management decisions. This finding encouraged us to reanalyze qualitative data collected during the study to explore the nature of self-management decisions being made by patients and how they perceived the role of their GP in this decision-making process.

Methods

This study is one component of a larger intervention study on self-management following stroke [26]. Ethics approval was received from relevant university and health authority human research ethics committees.

Participants

The participants in the study were 126 individuals who (1) had experienced their first episode stroke within the last few months or less, (2) were younger than 80 years (average age of 66.96 years), (3) had been discharged to the community, and (4) had sufficient expressive/receptive English language skills to participate in interviews. The participants were a consecutive sample recruited directly from an acute care setting in southeast Queensland, Australia. Of those who consented to participate in the broader study before discharge, 100 provided demographic, quantitative, and qualitative data. Of these participants, 67 were male and 33 were female, with an average age of 66.37 years (standard deviation 10.65 years). At the first follow-up, data were obtained from 91 of the participants. At the second follow-up, 81 participants provided data and 10 participants dropped out of the study for a range of reasons (six because of deteriorating health, one moved overseas, and three did not want to answer any questions). At the third follow-up, a further eight participants dropped out of the study, leaving 73 participants. At this time point, two participants had died, three could not be located, and three did not want to answer any questions. By the final follow-up, 71 participants remained in the study, with two participants dropping out without providing any reason.

Data collection

Semistructured interviews were conducted on five occasions over an 18-month period beginning before discharge from hospital and at 3, 6, 9, and 12 months after discharge.



Interviews were conducted by telephone and included four standard open-ended interview questions: (1) “What concerns you most about your present situation?”; (2) “Do you think your condition has changed since we last spoke?”; (3) “What do you think might change over the coming months?”; and (4) “Who provides you with the most help at the present time?” In accordance with the specific research questions addressed in this article, only responses to the last question were used in the analysis, and only as they pertained to GPs. In contrast to the broader study, which involved an in-depth qualitative investigation of how individuals managed during the first 18 months following stroke, this article focuses on specific questions about how participants interacted with their GPs. Not all participants made spontaneous reference to their GPs, but most participants commented on the role of general practice in responding to the last question. On average, each interview lasted about 1 h. However, the portion of the transcript pertaining to GP relationships was relatively small in most interviews.

Analysis

All interviews were audio-recorded, transcribed, and checked for accuracy. Any data pertaining to participants' relationships with GPs were identified and extracted. The selected data were thematically analyzed and coded by two independent researchers using multiple waves of coding until all relevant data had been explained [27]. The data were first examined by two researchers to generate the initial coding framework. Following agreement about this coding framework, one researcher categorized excerpts from the selected data into the codes and returned the data to the other researchers. All three researchers then reviewed the categories and refined the themes. The third researcher then described the themes in more detail using extracts from the selected text. Given that the initial interview questions did not pertain only to the GP relationship, it is not possible to determine whether or not saturation was reached. It is possible that further questioning on this topic might have revealed new information. The themes that emerged through this process are described in the following section with direct quotes from the data. Quotes can be identified by a unique reference that includes the individual's pseudonym and the data collection point (i.e. IV1, IV2, etc.).

Results

Overwhelmingly, participants described the importance of positive relationships with GPs and the way these relationships assisted them to adjust to, and manage, their life after stroke. Three major themes were identified that fully described the importance of this relationship and the ways in which the relationship could be detrimental. These themes included (1) critical sense-making, (2) validation of personhood, and (3) confirmation of actions.

Critical sense-making

The important role of GPs was highlighted by all participants across all time points following stroke: “[My GP] would be the most important person for me [in terms of providing support I see him about every two or three weeks ... for everything” (BillIV2). Participants expected GPs to help make sense of their experience; normalize ongoing symptoms, and provide information about, and estimates of, the extent and duration of their recovery: “[I want a] better understanding of what has actually happened to me, which I hope to find out when I go and see the doctor” (DonIV1). Often, GPs were expected to remedy misunderstandings or knowledge that had been inadequately addressed in hospital: “Speaking to my doctor, he has told me a few things that I don't know and that [the] hospital ... didn't tell me or couldn't tell me” (LynIV1). The GP's perseverance in working with participants to explore and find solutions was appreciated: “I've got a good local doctor ... he's tried different [medications] to [get] around [pain and epilepsy]” (JaneIV5). This role clearly continued to be important from the time of discharge over the first 18 months.

Although participants needed to make sense of their stroke experience, they were aware that GPs could not predict the full extent of poststroke recovery. As time passed, participants became more uncertain about their future, but they recognized that GPs were often equally uncertain. They valued the sense that they were not alone in that journey and that their GP would assist them as much as possible: “I'm fearful that it [stroke] could happen again I asked the doctors and they said I should be all right. But they're not giving me 100% answer, they don't know themselves” (JamesIV5). When GPs were unable to provide certainty, providing honest yet hopeful appraisals helped minimize the emotional impact of an



uncertain recovery trajectory: *“I use the phrase uncertainty. You don’t know what the prognosis is [or] what the degree of recovery is going to be But [GPs should] at least make people aware [of the uncertainty and slow recovery path] so their expectations aren’t misled”* (MariaIV4). When GPs addressed confusion and alleviated misunderstanding, patients reported high levels of satisfaction: *“[My GP] has been on the [cutting] edge of the stroke business ... she’s pretty knowledgeable ... pretty well switched on ... [she] can answer most of the questions I’ve got”* (MartinIV3).

Validation of personhood

Participants were constantly seeking answers, strategies, and solutions. In successful partnerships, GPs actively listened to their patients and involved them in decision-making through communication and negotiation: *“[My GP is] sympathetic ... terrific ... understanding ... compassionate ... interested ... and doesn’t think my pain is imaginary He doesn’t have that bored look on his face either [He is] extremely supportive in the way of allowing me to talk about my pain and so forth”* (JaneIV4).

This type of open communication validated participants’ experiences, giving them a sense of personhood, which ultimately enhanced the partnership: *“I can go down and talk to [the GP] about whatever is troubling me and he will give me a straight answer”* (RohanIV2).

Participants preferred continuous relationships with their GP – *“We’ve got a really good doctor that we’ve known for a long, long time. He’s a good doctor”* (JohnIV5) – because the GP thoroughly understood them as individuals – *“My doctor is very, very good. He knows my case history and all other things that I’ve had. He looks after me very, very well. He’s excellent”* (MarkIV2). Long-standing relationships between participants and GPs were underpinned by mutual respect, trust, and most importantly, value for the individual: *“I felt that the [GP] I had been with ... for so many years, I felt that he knew me as a person. So he knew my person before the stroke ... he didn’t treat me as an invalid. He treated me as [the] person I was prior to the stroke and he encouraged me to get back there”* (MariaIV4).

However, for some older participants, there was a belief that access to personalized care in general practice had

deteriorated because personal validation was no longer available, constrained by time and staff rotations: *“Twenty years ago you’d go to the doctor and they knew you ... nowadays they don’t ... years ago they used to take their time”* (FredaIV5).

Participants clearly preferred GPs who were warm and compassionate, and noted that collaborative partnerships were nonexistent when the GP lacked these qualities. When GPs dismissed participants’ priorities and concerns, participants felt devalued: *“I would change doctors if I could because she is interested, it seems to me, entirely in my diabetes [rather than any other health issues] I had a swollen ankle, the first time she didn’t take any notice, the second time she said, ‘oh, don’t worry about that, that’s only arthritis”* (DorothyIV5).

Apart from dismissal of their symptoms by GPs, some participants also reported dismissal of their personhood: *“You walk in there [to the GP’s surgery] and they immediately look at you as a stroke patient when you’ve gone in there for something else”* (MariaIV4). Feelings of having their personhood dismissed were exacerbated when GPs did not relate to participants as key players in their own health care: *“[The GP doesn’t] listen to you I get talked at as though I’m not there, [they talk to] somebody else”* (MariaIV4).

One participant expressed a particularly unhelpful relationship with a GP: *“[My GP is] just a very ordinary specimen of humanity He’s not a compassionate person I have no doubt he’s probably a competent enough doctor, but he’s not interested in people. He never shows you any warmth He’s a very cold individual”* (FrankIV3). Thus, quality communication with GPs was important for ongoing self-management decisions. For those who did not experience validation, there seemed to be a sense that they could not transfer to another GP. During the course of this study, these participants continued to experience negative interactions with their GPs, but did not seek other services.

Confirmation of actions

Participants demonstrated reliance on, and preference for, information received from the GP. There was a strong belief among many participants that the GP advice was right (even when experiential evidence suggested otherwise). Some participants believed that the GP would have given advice if it was



needed and that no advice meant nothing needed to be done, even in one serious case where the participant feared that he had had another stroke:

I feel I've had a minor [stroke] ... [but] I have an appointment with [GP] tomorrow. I didn't want to sort of rush over there and create a nuisance of myself. I thought 'I had an appointment for tests tomorrow' so I thought I'd do the whole thing together tomorrow [I'm] not expecting any glitches because my doctor virtually said that on this medication ... it's unlikely that I'm going to have another stroke. He never discarded the possibility that it won't happen but he said it's very unlikely and I just took his word (StephenIV3).

When GPs offered no advice, participants took this to mean that any management strategies were acceptable. In these circumstances, participants felt that they were individually responsible for deciding what they could or could not do, but often felt incapable of doing so without GP endorsement:

No, [GP] hasn't come up with anything [to help me]. No, no special instructions. I can do what I want to do. If I can, I can; if I can't, I can't. But he didn't tell me to do anything in particular (MatthewIV3).

Where I live ... there's nothing out there ... even my doctor hasn't suggested anything out here ... that's probably more [what has] made me mad than anything I don't know if it's up to me to get in[volved] with things (FredaIV2).

In the absence of clear GP advice, participants were often left feeling confused, uncertain, fearful and angry: “[I’m concerned] ... about what I can and can’t do. I am really confused about that – also a little bit scared” (LynIV1). Surprisingly, there were admissions from participants about actions they had taken that were contrary to advice received from other health professionals or through self-management training programs, often because they had not received the same, or indeed any, advice from their GPs. Often, any hint of disapproval, dismissiveness, or even ignorance from a GP about a

self-selected course of action resulted in abandonment of that action (e.g. exercise, complementary medicine, natural remedies). One participant described how “doctors [not other professionals] ... tell you [if what you’re doing is] right or wrong” (PeterIV5). This preferential status of GP information often went unchallenged.

Ineffective communication processes were most likely to damage the GP-patient relationship. However, instead of undermining the preferential status of GP information, poor communication meant that participants felt powerless. Without effective communication, negotiation was not seen as an option for many participants, and some developed strategies of resistance that inadvertently undermined their own self-management efforts: “I tend to tell my doctor as little as possible because he thinks I should be resting a lot more” (ElaineIV5). These participants remained dissatisfied with GP-dictated treatment regimens, but the lack of communication meant that dissatisfaction tended to increase: “I now find myself on ten pills a day ... everyone just wants to give me pills. It doesn’t fix it” (MariaIV4). The prescription of medications was an area where participants most actively voiced their concerns to the researchers, but where communication with GPs was most variable and strategies of resistance were most common: “[I] research myself and the naturopath. I talk to everybody. Doctor he said ... I have to increase my warfarin, but ... I researched so much to get the right diet [so I could avoid increasing my warfarin]” (VickiIV3). Other participants made independent medication decisions without communicating with their GP, which placed them at risk of complications: “I took [medication] for six weeks but didn’t notice any appreciable difference I noticed that I got a little bit of a stomach upset. So ... I’ve discontinued it. I won’t see [GP] now [for a month]” (FrankIV3).

In contrast, when willing participants were confident about their ability to communicate with their GP, they were more willing to discuss and participate in treatment (and medication) decisions: “Just communicating about medication and that sort of stuff. How long are you going to be on the heart and blood pressure tablets? How long are you going to be on these sorts of things?” (JeffIV5). Ensuring patient needs were met often required the GP to link with other community



resources. Participants clearly appreciated this collaborative approach:

Well the only thing I'm worried about is if I have another stroke. But the doctor has got me pretty well under control [The GP is working] with the chemist [The GP has] organized it all himself They confer and work together (MarkIV2).

[Stroke] is something that needs better understanding and perhaps [a] more understanding approach by ... the medical profession generally and by the ancillary professions when they're dealing with [stroke]; particularly when they're pushing people out the hospital door and saying, "ok buddy, you're on your own now" (MarkIV4).

Discussion and conclusion

Discussion

This study builds on an established body of literature pertaining to self-management support by exploring how people describe their self-management decisions following stroke in the context of their relationships with their GPs. The findings revealed that GPs played a crucial sense-making role, which enabled individuals to feel in control of their situation following stroke. When participants could no longer trust their own bodies [3], they relied heavily on existing relationships with their GP. An unpredictable recovery journey after stroke undermined participants' confidence in their ability to respond to what had happened to their body, or to interpret what was happening. This uncertainty was most prominent at the point of transition between acute care, rehabilitation settings, and return to community-based living, but continued over time for a large proportion of the participants. We found that participants were vulnerable to misinterpretation and uncertainty about how to apply self-management-relevant information that was provided to support these transitions. Therefore, they sought assistance from their GP to make sense of their stroke experience in the community. Although GPs could assist in the sense-making process, they could not predict what would happen in the future with certainty. In situations of combined uncertainty about the future, participants were comforted when GPs provided an honest appraisal of their current health status and situation.

Providing an honest appraisal was frequently predicated on a long-standing, trusted, and empathic relationship between GPs and participants. This relational continuity [28] was consistent with the notion of a collaborative partnership and was a source of personal validation and confirmation. These participants described positive and helpful self-management actions that were usually overtly supported or informed by their GPs. However, there was also evidence that some participants made self-management decisions that were potentially unhelpful, and indeed could be harmful, for their long-term health, especially with regard to medication management. These decisions were often associated with poor patient-GP relationships that provided no validation or confirmation. Poor relationships were also evidenced by the dismissal of participants' concerns, or a focus on health issues that were not the immediate reason for participants seeking the consultation.

Researchers have consistently found that ongoing contact with GPs provides an ideal opportunity for patients to discuss medication concerns, and has a positive influence on adherence with medication regimens [29]. However, we have found that it is not only ongoing contact but also whether or not that contact provides validation of the person and confirmation of the value of specific self-management actions that influences self-management behaviors such as adherence to medication regimens. Our finding has supported other researchers who have argued that patient-centered, collaborative communication was positively linked to medication adherence by people with cardiovascular disease [30].

Much of the literature implies that an effective partnership requires GPs to understand and legitimize the personal meaning of the illness [31, 32], ideally through the patients' eyes [33–36]. Recent reviews indicate that when GPs engage with people in clinically empathic ways (i.e. with understanding, by taking the perspective of the individual, and by communicating effectively), physical health outcomes for people with chronic disease are enhanced [37]. Thus, GPs need to explore both the disease and the person's responses from a broad perspective (i.e. in the context of patients' hopes, fears, beliefs, and resources). They also need to understand the whole person instead of just a set of symptoms [32, 38–40]. Developing an understanding of the whole person who is transitioning to life after stroke will require a balanced dialogue between



GPs and patients that is based on the contribution of different but equally important expertise from both parties during the sense-making process [41].

Although the partnership between the GP and the patient is central to self-management, there are likely to be structural, cultural, and economic factors that impact on the way in which individuals respond to a person-centered approach [42]. Our analysis has confirmed the critical role GPs can play in supporting self-management by understanding the context within which people live, validating that situation, and providing advice that complements the person's circumstances. Individuals reside within a web of social relationships that impact differentially on health behavior [30]. Thus, it is essential that GPs understand the social network and environment that surrounds their patients, where they fit within that network, and how the network impacts on health-related choices. This finding is supported by a recent literature review which found that although relationships between patients and physicians are mostly dyadic, perspectives that result from interaction with nonprofessional networks have an important influence on health behaviors [43]. It is important for GPs to interact with the health-related information that patients source within their networks, respecting the importance individuals place on that information [44] and appreciating the profound impact they can have on the patient's confidence in their own self-management actions.

Our study showed that GPs are an important part of participants' health networks, and therefore, that they need to be aware of that power. Partnerships were strained when patients felt that GPs did not respect their personal knowledge of their condition, or provided inadequate information and explanation [45]. Participants in the current study seemed unable to alter power imbalances between themselves and their GPs. Clearly, unless participants and their GPs had shared goals, a sustained working relationship, mutual understanding of roles and responsibilities, and requisite skills for performing their roles [46], it was unlikely that power and control would be equally distributed. Our data have confirmed that the balance of power between GPs and their patients requires a gradual shift toward a shared process, rather than a full 'pendulum swing' [47]. An optimal GP-patient relationship required consensus about both the problem and the management solutions

[34, 48], and willingness to adopt a new operating framework by both parties.

Conclusion

There is an increasing trend toward patient-centered care, shared decision-making, and self-management support in the general practice setting as mechanisms for optimizing the quality of the ongoing management of chronic diseases [12, 15, 19, 31]. Health professionals who aim to support self-management must acknowledge the complex contexts and embedded relationships within which self-management practice occurs [49]. The results of this study indicate that following discharge to the community, patients who have experienced stroke were primarily seeking support that assisted them make sense of their experience, validate them as a person, and confirm the value of their actions. However, when individuals with chronic diseases were making unhelpful self-management decisions, GPs needed to intervene as failing to do so was interpreted as confirmation. However, advice had to be given in a supportive nonpunitive way or it promoted resistance among some participants. For GPs, successful intervention required awareness of the inherent power imbalance within the relationship, open responsive communication skills, understanding of contextual factors, and sensitivity to the often-unspoken emotional responses of patients. It was expected that GPs could provide all this as well as being a repository of excellent medical knowledge and community resources.

Practice implications

Following a stroke, participants require validation of their personhood and confirmation that their actions are appropriate. Some patients do not have confidence that their GP will be able to meet those needs. It is imperative that we develop mechanisms for embedding patient-centered medical care within the clinical encounter. Specifically, we should explore ways of enhancing GPs' capacity to undertake sense-making, validation, and confirmatory actions despite existing funding restraints. Power imbalances and the impact they have on patient behaviors need to be reflexively monitored by GPs to ensure that appropriate self-management support is provided.

Conflict of interest

The authors declare no conflict of interest.



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