Patient-centredness in acute stroke care – a qualitative study from the perspectives of patients, relatives and staff

L. Busetto, C. Stanga, J. Hoffmann, H. Amiri, F. Seker, J. Purrucker, P. A. Ringleb, S. Nagel, M. Bendszus, W. Wick, and C. Gumbing for the Stroke Consortium Rhine-Neckar

Department of Neurology, Heidelberg University Hospital, Heidelberg; Department of Neuroradiology, Heidelberg University Hospital, Heidelberg; and Clinical Cooperation Unit Neuro-Oncology, German Cancer Research Center, Heidelberg, Germany

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Background and purpose: Although patient-centredness is considered a key component of high-quality neurological care, it is unclear to what extent it can or should be implemented during the acute phase. Using acute stroke as an example, the aim was to identify critical junctures for patient-centredness along the acute care pathway from the perspectives of patients, relatives and staff.

Methods: A qualitative multi-method study was conducted including 27 non-participant observations and 37 semi-structured interviews with patients, relatives and staff. Junctures were defined as critical when mentioned (as problematic) in two or three information sources (i.e. observations, staff interviews, or patient and relative interviews), as potentially critical when mentioned in one, and as uncritical when not mentioned.

Results: Post-procedure communication after thrombectomy, patients’ stay at the stroke unit and decision-making around transfer, discharge and rehabilitation were identified as critical junctures for patient-centredness. Arrival at the emergency department and the (thrombectomy) treatment itself were identified as uncritical junctures, whilst history-taking and treatment preparation, the treatment decision and patients’ stay at the intensive care unit were identified as potentially critical junctures.

Conclusions: In acute stroke care, patients, relatives and staff prioritize fast over patient-centred decision-making in the most time-critical phases, especially before and during treatment. This is reversed after the procedure, when difficulties arise implementing a patient-centred approach in clinical practice. To improve patient-centredness where it is most needed, clear guidelines and accessible resources are recommended. Future research should investigate whether insights from acute phases of stroke care are applicable to other neurological conditions as well.

Introduction

Patient-centred care – in which the individual patient and their needs are placed centre-stage – is considered a key component of high-quality care for many neurological conditions including dementia, epilepsy, Parkinson’s, multiple sclerosis and stroke [1-8].

However, as most efforts in research and practice have focused on patient-centredness in chronic (phases of) neurological diseases, it is unclear to what extent insights are applicable to acute neurological care as well. Specifically, when a patient is in acute need of medical treatment, there is often doubt whether time should be expended on ‘secondary aims’, potentially leading to ethical dilemmas or friction between staff and patient priorities.

One area in which this trade-off is especially visible is acute ischaemic stroke. Between symptom onset and
treatment, the average patient loses 1.9 million neurons per minute, eventually causing disability and death [9]. In many high-income countries, acute stroke treatment with intravenous thrombolysis (IVT) and/or endovascular thrombectomy (EVT) is increasingly provided in regional networks, consisting of hospitals only performing IVT (‘IVT hospitals’) and EVT-capable hospitals (‘EVT hospitals’). Currently, these networks use guidelines for treatment and transfer decisions focused on providing EVT as early as possible to increase patients’ chances for a good outcome. The individual patient’s needs and preferences during this process, and whether these are taken into account by treatment staff, remain largely unknown. This raises questions with regard to how patients and their relatives can or should be involved in decision-making and to what extent patient-centredness can or should be prioritized.

Using acute stroke as an example, this study aims to identify critical junctures for patient-centredness along the acute care pathway from the perspectives of patients, relatives and staff, in order to identify areas for improvement and potential transferability and applicability for other neurological acute diseases.

Methods

A consecutive qualitative multi-method design was used, including non-participant observations and semi-structured interviews, based on the COMIC model for the comprehensive evaluation of complex healthcare interventions from a broader (integrated) care perspective, allowing for the inclusion of aspects such as patient-centredness, shared decision-making or self-management support [10]. The Standards for Reporting Qualitative Research guidelines [11] were followed. Ethics approval was granted (Medical Faculty of Heidelberg University, S-682/2017).

Setting

The study was conducted at a comprehensive stroke centre providing endovascular therapy (EVT hospital) in the southwest of Germany. The EVT hospital (Department of Neurology, Heidelberg University Hospital) is one of the EVT sites and the coordinating centre of a regional stroke network (FAST; www.fast-schlaganfall.de), covering parts of three federal states and including approximately 20 hospitals.

Data collection

The core team responsible for data collection and analysis consisted of a social scientist experienced in qualitative research (LB), a speech therapist (CS) and a nurse (JH), all without involvement in patient care. Recruitment and data collection took place between March and June 2018. Planned and ad hoc observations were conducted at the EVT hospital’s emergency department (ED), angiography suite, intensive care unit (ICU) and stroke unit (SU) by pairs of two observers (LB, JH, CS) between March and May 2018. Preliminary insights from the observations informed the interview guides. Interviews were conducted between May and June 2018. A purposive sampling strategy was used to recruit interviewees from different professional groups and with different stroke pathway experiences aiming at a heterogeneous sample of approximately 20–30 interviewees. All interviewees provided informed consent before participation. Interviews were audio-recorded and transcribed verbatim. Interviews with patients and relatives were conducted approximately 1 month after stroke.

Data analysis

Interview transcripts were coded using MaxQDA software (2018, VERBI, Berlin, Germany) by two researchers (JH, CS), checked by a third (LB) and consolidated after discussions. Observation notes were transcribed into protocols by one researcher (JH or CS), checked by a second (LB) and consolidated into one protocol. Observation protocols were coded by one researcher (LB) using a short version of the interview coding schemes. The coding process included semi-open coding (informed by the theoretical framework but open to new findings), followed by axial and selective coding. Junctures were categorized as critical when mentioned (as problematic) in two or three information sources used (i.e. (i) observations, (ii) staff interviews, (iii) patient and relative interviews), as potentially critical when mentioned (as problematic) in one of the information sources, and as uncritical when not mentioned (as problematic). Quotes from interviews and observations were selected and translated from German to English by the research team to illustrate and explain main findings. Falterings and repetitions were excluded in brackets for improved readability.

Patient and public involvement

Members of a local stroke self-help group provided advice on the research design and helped pilot the interview guides for patient and relative interviews, which led to better wording and explanation of medical/technical terminology. Stakeholder validation of preliminary results was conducted with the Patient
Council of the Department of Neurology on 7 May 2019, which showed agreement with these findings outside of the study sample and provided topics addressed in the Discussion.

Results

General results

Twenty-seven observations were conducted with a mean duration of 134 min (median 90). Fifteen interviews were conducted with 16 staff members including neurologists, neuroradiologists, nurses, medical technical assistants and radiographers, social workers and therapists (occupational, speech and physical) lasting 37–97 min (mean 70 min). Sixteen patients and five relatives were interviewed. Of the patients, eight were female (50%), and median age was 64 years [interquartile range (IQR) 55–75]. Most patients had no pre-existing disabilities as indicated by a median pre-stroke modified Rankin Scale score of 0 (IQR 0–1). The mean National Institutes of Health Stroke Scale score at admission was 10.6 (SD 9.2). The primary hospital of 10 patients was the EVT hospital; the other patients were transferred to the EVT hospital after admission to an IVT hospital. The mean National Institutes of Health Stroke Scale score at discharge was 2.9 (SD 3.2). Median modified Rankin Scale score at discharge was 2 (IQR 1–3) and remained overall stable at follow-up (median 2, IQR 1–3). Of the five relatives, four were female, and the median age was 58, ranging from 27 to 72 years.

Critical junctures

Arrival at the ED and the (EVT) treatment itself were identified as uncritical junctures in terms of patient-centredness. History-taking and preparation of the patient for treatment, the treatment decision and the patient’s stay at the ICU were identified as potentially critical junctures. Post-procedure communication after EVT, patients’ stay at the SU and decision-making around transfer, discharge and rehabilitation were identified as critical junctures (Fig. 1). Exemplary quotes for each juncture are shown in Table 1.

Arrival at the ED

Several ED staff members indicated that when a stroke patient arrives their absolute priority is taking care of the patient. Whilst the patient is diagnosed and treated, the relatives generally have to wait outside (in the waiting area). Several relatives mentioned the fact that they had been waiting outside, with some reporting that everything went quickly and that they felt well informed by the ED physicians. One relative indicated that, even though she had to wait for information about the patient’s status, she was not necessarily unhappy about this (Q#1).

History-taking and preparation

According to ED staff, communication with patients during history-taking and preparation for treatment is influenced by their cognitive and emotional state. One physician explained that, under time pressure, history-taking has to be more focused on acute symptoms and on getting only the information needed for treatment decisions. Whilst the physician takes the patient’s history, two nurses usually also physically handle the patient, as was observed during patients’ preparation for computed tomography imaging (Q#2).

ED staff were observed to handle (potentially) privacy-sensitive situations differently. For example, some ED staff left doors open whilst patients were treated, including when patients were (partially) naked (Q#3). In similar situations, other ED staff tended to close doors or send people waiting outside the treatment rooms away. This difference was also observed with regard to conversations in the physicians’ room: whilst some physicians closed the door when talking about sensitive matters and avoided using names, others did not.

Nine patients partially remembered their journey through the ED, sometimes including being prepared for computed tomography imaging and treatment. None addressed the above issues around privacy and communication.

Treatment decision

In the emergency situation, patients or relatives are informed about treatment decisions and asked to give consent when possible, but an extended shared decision-making process usually does not take place. Reasons for this, according to staff, are the time-dependent treatment effect of EVT and IVT and the fact that in most cases these are the only viable treatment options and staff have to assume that the patient wants to get better (Q#4). Staff indicated that treatment decisions are more problematic when patients have severe pre-stroke conditions such as dementia or when it is known that the patient would not want certain treatments (Q#5).

Some patients and relatives said that they were not informed about IVT or EVT, or that they did not remember whether it was addressed in that moment. Some said that they were informed about the
treatment options, whilst others said that they did not remember whether they were informed or asked about them (Q#6, Q#7).

One patient described how he had just let everything happen to him and hoped that they would be able to help him, whilst another patient emphasized that he trusted that the physicians would take the right decision for him. No patient or relative described this situation as negative or indicated that they wished for the situation or decision to have been different.

**Treatment**

Patients are either intubated or in conscious sedation for EVT and often unable to understand what is happening around them. When patients are not intubated, staff tell them what to expect and how to behave during the procedure. Even when patients are not able to understand them, staff will try to soothe them with a calm voice. However, staff pointed out that this should not be a priority over successful treatment (Q#8).

Five patients who had remained at least partially conscious described their memories, ranging from a few vague impressions such as the room being dark, to being fully conscious throughout the entire procedure, relating conversations they had with the interventionalist. Of these, two patients indicated that they trusted the interventionalists, and one patient said that she had felt that everything was under control and that she had all the information she needed at the time.

**Post-procedure**

After EVT, patients were sometimes, but not always, informed about the outcome of the procedure (Q#9). There is usually no contact with relatives during the intervention as they remain in the waiting area and

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**Figure 1** Overview of critical, potentially critical and uncritical junctures in terms of patient-centredness along the care chain. ‘Arrival’ refers to patients’ arrival at the emergency department; ‘Stay @ ICU’ refers to patients’ stay at the intensive care unit; ‘Stay @ Stroke Unit’ refers to patients’ stay at the stroke unit; ‘rehab’ refers to rehabilitation. ‘X’ indicates that the juncture was described (as problematic) in the observations, staff interviews (‘staff’) or patient and relative interviews (‘patients & relatives’).
| Juncture                          | Quote                                                                                                                                                                                                                                                                                                                                 | #  |
|----------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----|
| Arrival at the ED                | *On the one hand I would have liked to know; on the other hand I’d say it was a good thing that I didn’t know, otherwise it would have driven me even crazier.* Relative, Interview 17                                                                                                                                         | 1  |
| History-taking and preparation   | *Parallel to the examination [by the physician], a nurse takes the patient’s temperature in her ear. The patient startles and is distracted from the physician’s examination and stops following the physician’s instructions.* Emergency Department, Observation 13                                                                                                                                  | 2  |
|                                  | *While the [urinary] catheter is being put in place, the patient is lying on the bed naked from the waist down [...]. The nurses have put both her legs on the edges of the bed. The door of the treatment room is open. Several people are standing outside the treatment room and are able to look into the treatment room.* Emergency Department, Observation 1 | 3  |
| Treatment decision               | *Of course, we tell the patient what we do, but that’s more [...] in order to pass on information. [...] I have seldom heard that someone said: “No, I don’t want you to do this procedure. My father used to be healthy, but I want him to be a case for nursing care now.”* Physician, Interview 10                                                                                      | 4  |
|                                  | *If you have a patient who is severely pre-morbid and who is already dependent on care and where the chances aren’t high that you can do something good for the patient, then after consulting with [colleagues] and family members. [...] you may decide together that maybe it is not good to provide the treatment [...] But those are by definition difficult decisions that need to be taken in a minimum amount of time.* Physician, Interview 5                                         | 5  |
|                                  | *I can’t remember if I was asked. I don’t know. I think it was more like an information for me. Maybe I did say "yes", maybe it was more of a question, I don’t know.* Patient, Interview 1                                                                                                                                         | 6  |
|                                  | *Relative: ‘[The physician] advised us to have it done, basically [to go] through the groin, upwards, to have a stent put in and have [the clot] sucked out or dissolved medicinally [...].’ Patient: ‘[The physician] said: “You have to take the decision, but I can tell you right away: it would be better.” And that was the decision, that we both said we’ll have it done. Even though there is a certain risk to it.’ Patient and relative, Interview 8                          | 7  |
| Treatment                        | *But still, [...] you have to recognize the moment when talking and soothing do not help anymore [...] and then you may have to react to [the patient’s] disquiet with an intubation, to prevent worse things.* Nurse, Interview 15                                                                                                           | 8  |
| Post-procedure                   | *The radiographer starts cleaning the angiography suite. [The patient] is not informed about what is going on. She is still lying on the angiography table with her shirt pulled up.* Angiography, Observation 18                                                                                                                                      | 9  |
|                                  | *Interviewer: ‘How did you know [the patient] would be [transferred to the SU]?* Relative: ‘I saw her and then I went [with her to the SU]. But no one talked to me.’ Relative, Interview 4                                                                                                                                  | 10 |
| Stay at the ICU                   | * [...] Because you are so unsure. [...] If you go there constantly, if someone is constantly getting on [their] nerves, constantly asking [...] [Laughs.] Not that the care is worse, but maybe [they think]: now she’s coming again…* Relative, Interview 2                                                                                     | 11 |
| Stay at the SU                    | *I could never rest [at the SU]. It was very bad. [...] The machines and then the nurses [...] who talked loudly [...]. That wasn’t good. I didn’t like it.* Patient, Interview 5                                                                                                                                          | 12 |
|                                  | *It’s extremely loud [...] on the ward [...]. New patients are arriving almost constantly, or someone leaves, or someone is screaming the whole night. We need to keep the doors open to keep an eye on the patients and that’s certainly not an environment [for them] to rest.* Physician, Interview 9                                                                   | 13 |
|                                  | *I told them a few times: “Can you show me the X-rays?” [...] I’ve never seen them. [...] I mean, if I know what’s happening to me, I can ask questions.* Patient, Interview 10                                                                                                                                            | 14 |
|                                  | *In the moment it was [...] clear to me what [the neuroradiologist] had done [but] when I think about it, then [...] I picture it, then I want to know it in more detail. But at that moment [the neuroradiologist] wasn’t there anymore.* Patient, Interview 9                                                                                     | 15 |
|                                  | *I listened to no one except my wife. [Laughs.] I didn’t really understand anyone [else] [...] I had hoped for it to be a bit clearer.* Patient, Interview 9                                                                                                                                                | 16 |

(continued)
are informed about the patient’s health status and whereabouts only afterwards. Sometimes, however, this communication did not take place or was perceived as problematic (Q#10).

**Stay at the ICU**

At the ICU, patient room doors are usually open, including during physicians’ rounds when discussions take place in and outside the patient rooms. In the interviews, staff emphasized the importance of explaining the situation to the relatives and recognizing the extreme emotional state many relatives are in. During the observations and in one patient interview, it was described how ICU physicians repeatedly asked when relatives would visit again because it would be beneficial to the patient. Still, one relative worried about whether her level of involvement in her mother’s care would be perceived negatively by ICU staff (Q#11).

**Stay at the SU**

Similarly to the ICU, patient room doors at the SU are often open and physicians’ rounds are conducted with open doors and include discussions in the corridor. It was observed as well as agreed by patients, relatives and staff that the high noise and temperature levels (in the summer months) were perceived as problematic (Q#12, Q#13).

Staff pointed out patients’ fragile emotional states, describing many as surprised, uncomfortable, sad, insecure or afraid. Physicians were observed to explain the treatment plan to patients and ask whether they had questions, but in the interviews SU staff described patients’ difficulties in understanding and remembering their diagnosis as well as the severity of what had happened to them, which was confirmed by patients and relatives. Several patients and relatives said that they felt (sufficiently) informed afterwards and were able to explain the procedure they had undergone to the interviewer. Other patients said they did not know anything about the treatment, with some not remembering whether information had been provided and others specifically stating that it had not been provided (Q#14). Whilst one patient said she had only been told that ‘there was a band-aid’ and ‘that something had been done there’ (Patient, Interview 3), another patient expressed a wish for more time to ask questions (Q#15), and a third said that whilst he knew that information had been provided to him he had not been able to understand it (Q#16).

In general, SU staff stated that they are aware of relatives’ needs and that they try to keep them involved. However, time constraints can make this difficult and some relatives’ expectations were described as unrealistic. One physician in particular stressed a clear prioritization of patients’ over relatives’ needs, stating that ‘if three new patients arrive, talking to relatives is not important’ (Physician, Interview 9). Whilst some relatives indicated that they felt involved, listened to and welcome, others expressed wishes for more time and (emotional) support by staff.

**Transfer, discharge and rehabilitation**

The level of patients’ and relatives’ involvement in discharge, transfer and rehabilitation decisions varies. These decisions were mainly observed to be communicated to the patients rather than discussed with them, but sometimes physicians asked patients about their preferences or patients spontaneously expressed these. Several patients said they had been informed about their discharge or transfer to their referring hospital ‘as a fact’, which they accepted. Other patients described how they felt they had actively taken part in and influenced the decision, often deciding against
more treatment (Q#17). Two patients declined rehabilitation because they had other medical conditions they felt they had to prioritize over further stroke treatment.

Other patients and relatives specifically reported not having been consulted or involved (Q#18, Q#19), with other observations and interviews also indicating a more limited involvement by patients and relatives (Q#20). One patient was happy about not being involved in the discharge decision, since ‘if it had been [his] choice, [he] would have gone home the very next day’ (Patient, Interview 12).

Discussion

Using stroke as an example, this study identified critical junctures for patient-centredness along the acute care pathway. Our research has shown that patients and relatives have not indicated an immediate wish for more patient-centredness in the hyper-acute phase where actions need to be taken most urgently. Staff and patients seem to be in agreement about this more limited level of patient-centredness right before and during IVT and/or EVT provision. However, later on and when more time is available this trend is reversed, with the most critical junctures occurring post-procedure and during patients’ stay at the treatment wards.

Comparison to other studies

Patients’ arrival at the ED was categorized as uncritical, with staff following clear guidelines regarding their prioritization of patient over relative interactions and with relatives feeling sufficiently informed by staff or accepting the situation as it was. History-taking and preparation were categorized as potentially critical, based on observations of potentially privacy-sensitive situations handled differently by staff members. Other studies suggest that staff might prioritize safety considerations and risk avoidance over dignity and privacy, believing to act in the patient’s best interest, and the built environment making privacy concerns difficult to comply with [12-17]. Our patients did not mention these issues when asked about their memories of the ED, possibly due to methodological factors (such as our patient sample not having experienced or not remembering these situations) or some patients preferring to leave decisions to their physicians or making a (perceived) trade-off between the fastest possible versus patient-centred care [18,19].

The treatment decision was discussed in neutral to positive terms by patients and relatives, who did not indicate a wish for (more) patient-centredness. IVT or EVT indication for patients with severe pre-stroke conditions or patients for whom a good clinical outcome is unlikely was discussed as problematic by staff members. Further research is needed to investigate how physicians can be better supported in these critical cases not covered by guidelines and whether patient (representative) involvement could potentially support this, as has been explored for palliative and end-of-life care [20-24]. Patient (representative) involvement in guideline development has been recommended and trialled for various conditions [25-32], and several countries use patient (representative) committees for guideline development in stroke as well. Future research should investigate its applicability for the hyper-acute stage including the criteria for patient ‘selection’ for transfer and treatment.

The EVT procedure was categorized as uncritical, with many patients not remembering it and those remembering describing it in neutral to positive terms. This is counterbalanced by information deficits after the procedure, even though at this point the less time-critical phase of care begins. Other EVT research corroborating or contradicting these findings is not known, but studies investigating in-house care transitions, including between specialties and after surgery, also reported the need for improved communication, although focusing mainly on communication between clinicians [33-35].

Patients’ stay at the ICU was potentially critical as relatives worried about the impact of their involvement on staff’s attitude towards them or the patient. These findings are in line with studies emphasizing the ambiguity and uncertainty experienced by relatives regarding their role in patients’ care, but also confirming the importance attributed to family member involvement reported here [13,15,17,36,37].

The patient’s stay at the SU and transfer, discharge and rehabilitation decisions were categorized as critical. First, the general ward environment was perceived as not allowing patients to rest. This is in line with other studies emphasizing the negative impact of the physical environment, especially on patients with cognitive impairment treated on acute wards [12-15,17,36]. A second critical point relates to the question of to what extent patients and relatives were informed about past and future treatments. In addition to the studies reporting challenges for family member involvement cited above, one study into staff perceptions of caring for people with dementia in the acute setting stressed that staff should take better into account that even people with cognitive impairment can communicate their needs if given adequate support [15]. As such, SUs might consider making use of communication strategies developed for cognitively impaired patients due to possible similarities to...
challenges experienced by stroke patients in the early phase. The third critical point relates to discrepancies with regard to whether and when patients and relatives were involved in transfer, discharge and rehabilitation decisions. Challenges regarding appropriate and timely discharge planning were also reported in other studies [13,15,38] with one citing a discharge nurse as the main facilitator for improved discharge processes [36], the applicability and feasibility of which might also be explored for network-based stroke care.

Limitations
Our study was limited to a single centre and did not incorporate observations at referring hospitals which limits the applicability of insights to IVT hospitals – which it is planned to address in a follow-up study. Moreover, our patient sample overall showed very good recovery from stroke, which probably affected our results as patients and relatives may be more grateful or look back more positively on decision-making with a positive outcome. Future research should include severely affected patients (before and after stroke), including those not transferred for EVT and those dissatisfied with treatment decisions. Finally, even though observations provided a more objective framework within which to interpret the results from the interviews, future (mixed methods) research is needed to investigate potential discrepancies between actual and perceived reality.

Scientific and practice implications
Our findings provide guidance regarding the areas in which resources for more patient-centred approaches should be invested. Staff education for increased awareness as well as in-house guidelines on potentially privacy-sensitive situations and the appropriate level of patient and relative involvement should be considered. Small changes such as a standardized relative update post-procedure could have a considerable positive impact in moments of extreme anxiety. Hospitals should also consider investing resources for more timely, appropriate and accessible information provision to patients and relatives, both disease-specific and with regard to the most beneficial form and level of their active participation in the patient’s care. These resources should be made accessible for patients (temporarily) exhibiting lower health literacy and intellectual capacity, and relatives in crisis. Future (qualitative) research is needed to better understand those junctures identified as critical and potentially critical, especially by widening the groups of study participants to include more severely affected patients and their relatives. This would also make it possible to investigate controversial topics, such as treatment decisions (including preferences for treatment limitation), from a more diverse group of stakeholders. In addition to studying the different perspectives of these groups, future research should also investigate the extent of their agreement with each other, for example using focus group or Delphi designs. Lastly, further research is necessary to investigate whether insights from the stroke setting are applicable to the acute phase of other neurological diseases as well (e.g. hospital admissions for status epilepticus, meningitis/encephalitis).

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Disclosure of conflicts of interest
The authors declare no conflicts of interest related to this study.

Data availability statement
No data are available. As per the ethics vote, access cannot be provided to observation protocols and interview transcripts. Re-use outside the research team is also not permitted as per the ethics vote.

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