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# **BMJ Open**

# General practitioners' views and experiences in caring for patients after sepsis - a qualitative interview study

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Title: General practitioners' views and experiences in caring for patients after sepsis - a qualitative interview study

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#### **Abstract**

### Rationale

Patients surviving critical illnesses, such as sepsis, often suffer from long-term complications. After discharge from hospital, most patients are treated in primary care. Little is known how general practitioners (GPs perform critical illness aftercare and how it can be improved. Within a randomized controlled trial, an outreach training programme has been developed and applied.

#### **Objectives**

The aim of this study is to describe GPs' views and experiences of caring for post-sepsis patients and of participating a specific outreach training.

#### Design

Semi-structured qualitative interviews

#### **Setting**

- 14 Family practices in the metropolitan area of Berlin, Germany
- 14 GPs, who had participated in a structured sepsis aftercare program in primary care

#### Results

Themes identified were: Continuity of care and good relationship with patients, concentration on everyday functioning and lack of information about the intensive care unit (ICU) stay. An outreach education as part of the intervention was considered helpful to improve GPs' knowledge of the management of post-intensive care complications.

#### Conclusions

GPs approach to patients surviving sepsis supports providing individual and continuing aftercare. Better communication at the ICU-GP interface and training in management of long-term complications of sepsis may be helpful to improve aftercare.

**Keywords:** post intensive care syndrome, sepsis, primary care, General Practitioner, after-care, outreacheducation, qualitative research

#### **Abbreviations**

GP: general practitioner

ICU: intensive care unit

PICS: Post-intensive care syndrome

SMOOTH: Sepsis survivors monitoring and coordination in outpatient health care

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#### **Article Summary**

- Most sepsis survivors are treated by their GPs in the long term
- There is a lack of specific knowledge about sepsis complications in primary care
- Information flow from intensive to primary care should be improved
- Outreach education on post-sepsis complications may support GPs providing aftercare



#### **Introduction**

An increasing number of patients are treated in intensive care units (ICUs) and survive a critical illness such as sepsis<sup>1</sup>. After discharge, patients may suffer from long-term consequences<sup>2</sup>, such as critical-illness-polyneuropathy, critical-illness-myopathy, cognitive decline, chronic pain<sup>3-6</sup>, depression or post-traumatic stress disorder<sup>3, 7, 8</sup>. These sequelae are referred to as the "Post-intensive care syndrome" (PICS)<sup>1</sup>. They result in lower health-related quality of life and elevated mortality rates, as well as increased health care use<sup>9-11</sup>.

International guidelines state that patients with post-intensive care syndrome should have ongoing, longterm monitoring and therapy<sup>12, 13</sup>. Some patients discharged from ICUs are referred to ICU follow-up clinics. The purpose and structure of these clinics vary between countries, but change of clinical outcomes are rarely shown<sup>14-16,20</sup>. In addition, continuity of care at an ICU-follow up clinic may be difficult, when the patient lives far from the ICU and needs frequent follow-up<sup>17-19</sup>. Even if intensive care doctors and nurses are familiar with complications after critical illness, their role in coordinating ICU follow-up is discussed controversially<sup>20,21</sup>: They seem not to be trained in outpatient care coordination and the clinical variety of possible post-ICU complications<sup>20</sup>. Additionally, they do not know their patients for long and therefore may lack insight into the patient's psychosocial background<sup>22</sup>. On the contrary, GPs have a long-lasting relationship with their patients and provide care coordination as a core task<sup>23</sup>, which is highly appreciated by the patients<sup>24</sup>. This makes GPs ideal advocates of patients in their rehabilitation pathways. Thus, a Dutch retrospective cohort study found an increased consultation rate in primary care following ICU discharge<sup>25</sup>. Considering, that there were more than two million intensive care treatment cases just in Germany in 2017<sup>26</sup> and an assumed increase driven by the Covid-19 pandemia, GPs need to know how to provide best post-intensive care to these patients, as it has been already called for by others<sup>27</sup>. The concept of the PICS is quite recent, but GPs intensive care experiences may date back to medical studies or early hospital rotations. In a qualitative study, GPs reported lack of background knowledge and confidence in diagnosing and treating post sepsis complications<sup>28</sup>. Kahn (2007) states that GPs need to be educated in how to care for patients after critical illness but do not provide suggestions about how this should be done<sup>22</sup>.

Outreach education and academic detailing appear to change physician behavior and improve care<sup>29</sup>, but current evidence mainly focuses on changing prescribing patterns rather than on complex treatment strategies. Educational outreach visits providing knowledge to primary care for relatively rare medical problems are shown to enhance confidence<sup>30</sup> and are acceptable to GPs<sup>31</sup>. Such an intervention may be effective in educating GPs in

how to effectively care for patients with post-intensive care syndrome. However, whether it is needs to be assessed.

The SMOOTH trial evaluated a structured after-care program in general practice for sepsis survivors including an outreach education for GPs<sup>32, 33</sup>. Sepsis is one of the leading causes of long-term-ICU stays and can be viewed as a model illness for critical disease<sup>34</sup>. As part of this trial, in-depth interviews were held with GPs to explore their experiences with patients discharged from ICU and the intervention. Qualitative research has been conducted with post-ICU patients in detail<sup>35-37, 38, 39, 47</sup>, but, to date, no one had explored in depth the views and experiences of GPs caring for these patients. The aim of this study is to describe GPs' views and experiences of caring for post-sepsis patients and of participating a specific outreach training, in order to inform and contribute to applicable future aftercare structures in primary care.

#### **Methods**

#### The SMOOTH-trial

The SMOOTH trial is a multi-center RCT evaluating a primary-care based aftercare-intervention for sepsis survivors. The intervention included monitoring of the patient by a case manager (a specialized nurse), a patient education session delivered by the case manager and an educational outreach-visit by a liaison physician to the GP, details are reported elsewhere<sup>32</sup>. Patients were recruited in the ICU and when they agreed to participate, their GPs were contacted and asked to join also the trial. 291 patients agreed to participate, with 148 patients were randomized to the intervention and 143 patients to the control group receiving usual care. As some patients changed their GPs during the trial, the number of GPs was slightly larger than the number of patients. 307 GPs were approached to participate. 294 (95.8%) agreed and were included in the trial. Of total 159 GPs in the intervention group, 55 were recruited at the Berlin trial site.

The intervention directed at the GP consisted of one outreach educational visit by a liaison physician - a GP trained in sepsis aftercare. The visit was scheduled after the patient's discharge and according to time preferences of the GPs. It took place in the GP practice and lasted about one hour. The education session included a brief overview of sepsis epidemiology and diagnosis, including red flags in primary care, but focused specifically on the six most common sequelae of sepsis ("Sepsis Six"). The epidemiology of long-term sequelae, practical tools for diagnoses and monitoring, as well as evidence-based therapeutic options in routine outpatient care were presented. A detailed manual covering all the information given and a brief sepsis pocket-card summarizing main points for everyday practice were handed over to the GP, published elsewhere<sup>33</sup>. The GP was

asked to contact the liaison physician later at any moment in the study if questions arose during follow-up of the patient.

#### Study design and data collection

As part of implementation evaluation, semi-structured interviews were held with the GPs in the intervention group of the RCTs to gain insight into their experiences caring for patients surviving sepsis and the GP education that had been delivered as part of the intervention.

Qualitative methods are applied within the paradigm of critical rationalism. The aim was to understand the GPs view of the patient's situation as a starting point of aftercare and the functioning of the intervention from the GP perspective. We purposefully sampled GPs for interview to ensure interviews were held with GPs of varying gender and duration of work experience. All those approached for interview had worked at the Berlin trial site.

If GPs were willing to be interviewed, they were posted information about the interviews and a consent form.

A 4th year medical student (NS) who had received training in how to conduct qualitative interviews conducted the interviews as a research project within the regular medical curriculum. She was part of a qualitative research group and received regular supervision from two of the other authors (SGB, CH) who are experienced in qualitative research.

GPs willing to be interviewed could stipulate the time and location of their interview. A topic guide was used to ensure consistency across the interviews, see Table 1A/B. It covered the GPs' perception of post-sepsis patients and their symptoms as well as their experience of caring for these patients and of the educational session. The first interview was used as a pilot but as no changes were made to the topic guide, the interview was included in the analysis. With participant consent, the interviews were audiotaped and transcribed verbatim by NS. GPs were interviewed until data saturation was reached, i.e. when no new themes were identified in the later interviews.

#### **Patient and Public Involvement**

Patient's perspectives and needs were included into topic guide development by the study team. Beside literature research, it was based on the results of qualitative interviews with sepsis survivors, using the same methodical approach and being published elsewhere<sup>47</sup>.

#### Data analysis

The interviews were analyzed thematically<sup>40</sup>. Inductive thematic coding was used to gain an overall insight into the perspectives of the GPs. Transcripts of four interviews were read and re-read by different members of the research team (SGB, CH, KS, JG) who identified themes and developed initial coding frames. These researchers repeatedly discussed their codes and interpretation of the data. Once the coding frame had been agreed, it was applied to all interviews. Coding was done manually by SGB. Results were presented to the research team and discussed until consensus was reached (SGB, CH, JG, KS).

#### Results

#### **Participants**

We contacted 18 GPs for interview. Four GPs declined to participate due to lack of time. The 14 GPs who agreed to be interviewed (tables 2 A/B and 3) choose to be interviewed at work, on practice premises, in a private room. After 14 interviews, theoretical saturation was reached with no new aspects emerging in the last two interviews. The interviews lasted 12–28 minutes (mean 20 minutes). Themes considered relevant to this paper with corresponding quotes are shown in tables 4 and 5.

#### Caring for patients after critical illness

When analyzing the GPs' accounts, three main themes related to their experience of caring for patients after intensive care were identified as continuity of care and good relationship with patients, lack of information during the acute illness and individual impact of persisting symptoms after discharge.

### Continuity of care and good relationship with patients

At the start of the interview, the GPs were asked to talk freely about their patient. The accounts given suggested that specific medical diagnoses and the acute sepsis diagnosis played a limited role in the GPs' narration. GPs often commented on the patient's condition before they were diagnosed with sepsis, discussing their pre-existing disease and previous general health status. It was evident that many of them were familiar with the patients' medical history.

Many GPs also talked about the patient's personality. They often focused on the patient's coping and illness behavior as one GP explained:

"... she is actually a very modest... and shy person and for her medical problems she only claimed what she really needed urgently at that moment. A very kind and pleasant patient." GP 12

Some GPs also reported on the personal and employment situation of their patients, especially if they felt that this had been important to the recovery of the patient:

"Despite being my age, she had a young daughter and I think that's why she needed to be functioning and go back to work and she needed the money, yes." GP 6

Even if most GPs seemed to know their patients very well, two GPs stated that they started caring for their patients only after the sepsis hospital stay. These two GPs gave little information about their patients.

#### Lack of information during acute illness

Most GPs commented that they lacked information about the acute sepsis event. They had not been informed about their patient's condition or involved in any of the treatment decisions made whilst their patient was in hospital. Several GPs could not specify the exact diagnosis and focus of the sepsis.

"The event of sepsis itself, as I said, wasn't diagnosed by me, in the practice, but happened in hospital after the operation and that's why I sort of got him back here as everything was finished. I just had to sort of accept that (...) in the end, I didn't have much to do with it and that's why I don't know much about it. "GP 8

Some GPs perceived the acute sepsis event as a tragic lifetime event for their patients and discussed the emotional impact of the serious impact on the patient and his/her family.

"This was a very unlucky course of events (...) surely, everybody asks, why is it just me?" GP 3

#### Individual impact of persisting symptoms

GPs mentioned a number of different aspects when they described the condition of their patients after discharge and the impact of sepsis sequelae in their quality of life: general weakness and low functioning, the impact of preexisting diseases, individual specific health impairments and – less frequently- specific diagnosis of long-term-complications contributing to the post-intensive care syndrome.

Many interviewees described a general weakness and low functioning of their patients. They attributed this to the severe illness and the long hospital stay, without specifying the factors and causes contributing to the weakness like underlying illnesses, specific complications or treatment side effects. The focus of their reports

was on the consequences for independence and autonomy of their patients rather than underlying pathomechanisms.

"Well, she was a shadow of her former self" GP 6

Many GPs compared their patients' health status to their condition before critical illness. In some cases, they saw their patients' impairment after discharge as, at least in part, attributable to pre-existing and chronic illness. In their perception, the acute sepsis event did not alter status of these patients much.

"Essentially, he kept the diseases he had before and everything got gradually a bit worse. He tended to be depressive before and now it isn't much worse." GP 11

The report about their patient condition and complications after sepsis was in many cases given in common, everyday language without listing specific medical diagnoses or specific sepsis complication. They rather concentrated on reporting on everyday functioning and overall well-being. Only some GPs classified specific sepsis sequelae and precisely stated these diagnoses. Some added being only aware of the diagnosis after the education session, they received as part of the study intervention.

"And mainly... he was quite distressed by the gait disturbance; by the painful paresthesia he had (...) the polyneuropathy was what was left from the sepsis syndrome." GP 8

Some GPs reported individual complications of sepsis or sepsis therapy had the main impact on the patient's quality of life afterwards, e.g. the loss of a limb or a persisting colostomy.

"As she had, because of this sepsis, she basically lost the leg, well, she had an amputation and ...hmm...she was still quite mobile before and could leave the flat. Hmm, afterwards no longer, because with one leg she couldn't manage the stairs." GP 5

One GP could not contribute to that aspect, as his patient died shortly after discharge.

# Impact of the outreach education

Three main themes that described the impact of the education session were identified: acceptability, increase in knowledge, and the transfer to professional practice.

Acceptability

Most participants stated that they appreciated the time and the effort on the side of the liaison physician to come to their premises and adapt to their schedule. They commented that this was an advantage for their own time schedule and comfort.

"I was approached at a time that was convenient for me (...), I didn't need to move anywhere, that could happen here, well, the colleague bothered to come (...) and as I said that was ideal, I would say." GP 2

However, some GPs said they had many patients to care for and tasks to cope with and could not spare any time for the training. A few also mentioned that post sepsis patients are rare in a GP practice and that they would rather invest save time in continuing education for more common diseases.

"Well, it was very interesting, the education, but this is just another additional point, that takes time and I would prefer e.g. to have lunch or something similar." GP 11

#### Improvement of knowledge

The majority of practitioners stated that they had gained new knowledge from the education. Many interviewees reported it was new to them that sepsis can cause specific disease sequelae persisting after hospital discharge.

"Yes, that was largely new to me, that sepsis is seen as a complex illness with long lasting complications.

Till now, I saw it more as a complication, that, when cured, is resolved." GP 11

GPs often also stated, that they weren't aware that mortality is still elevated long-term after discharge until they heard about that in the education session.

"Most helpful was (...) that sepsis e.g. has a high mortality, the numbers were alarming! I mean, the mortality after discharge, (...) basically, I thought: Sepsis survived, ok, the bird flies on." GP 2

Some of the GPs reported that they did not know before that polyneuropathy and psychological problems were common consequences after sepsis and intensive care.

"I think, I would not have seen the connection before. Because she had so many other reasons for a polyneuropathy, I would have probably linked it to the diabetes." GP 5

One GP acquired more information about diagnosis of a sepsis in a patient, even though that was not in the focus of the education session.

Some GPs stated that they already knew the information given to them, but even when this was the case, they still appreciated the repetition and summary preparing them for the care of the patient.

"Well, I didn't find anything really new to me. But it was brought back and I did concentrate on it and looked closer to it. That was new to me and helps me for, well, aftercare." GP 9

One doctor saw no benefit from the education; he had done research in this field before his GP work and had the relevant knowledge before.



#### Transfer to practice

Most of the GPs interviewed said that the new information helped them care for the patient included in the trial, and that it would help them in their future work with similar patients. Most of them saw a benefit in identifying sepsis sequelae.

"...mainly the polyneuropathy and so on, I look out for it more closely. I say to myself: Look out! You must keep that in mind and ask for it, when they don't tell on their own, if they have problems." GP 5

Some reported consequences for the therapy of the patient they cared for within the study and some stated that they would probably change their therapeutic approach to similar patients in the future.

"I believe I changed some things afterwards. I mentioned the psychotherapist afterwards, that became quite clear, and (patient's name) did agree to that." GP 4

One GP had quickly diagnosed a patient with acute sepsis since the training, even though diagnosis of sepsis was not its main focus.

Some GPs doubted the relevance of the information for their work. They stated that caring for similar patients was a very rare event in their practice, and therefore they did not think they would apply the knowledge they had learnt.

"I don't have any sepsis patients - that's why I can't change anything about what I do." GP 3

### **Discussion**

Findings from this study suggest that GPs provide continuity of care and a good relationship with patients and consider pre-existing and chronic disease, personality and coping patterns, as well as social background, when providing post-ICU-care to patients. Many interviewees described the long-term impact of sepsis on their patients as a general weakness and malfunctioning and considered it in relation to the patient's pre-sepsis constitution. Some GPs expressed empathy with the serious life event their patient experienced. GPs reported a lack of information about the course of the disease and their patient's condition while they were in the hospital. Diagnosing and listing specific sepsis sequelae played a minor role.

The outreach education session was acceptable to most GPs. Most GPs acquired new information about long-term-complications of sepsis. They considered this information as helpful to identify and start treatment for

specific post-sepsis symptoms. However, some GPs did not value it and pointed to the small numbers of post-sepsis-patients being in competition with other patients and tasks.

While most of the GPs' accounts suggested a long-standing knowledge of the patient and an individual appraisal of their health impairments after discharge, they lacked detailed medical knowledge about sepsis complications. The outreach education was mainly well accepted and seemed to provide a valid setting to improve knowledge about specific diagnostic and therapeutic concepts GPs can apply in their professional practice.

#### Comparison with existing literature

Patients' perceptions of their quality of life after an ICU-stay have been examined in several qualitative studies. A wide range of ongoing health impairments was identified and loss of autonomy was a main aspect<sup>35, 37</sup>. The views of the GPs identified here is very close to patients' perspectives. The GPs also reported general weakness and low functioning as a main aspect and that a very individual apprehension of complaints and impairment. This congruence may facilitate a patient-centered after-care especially in a primary care setting.

Difficulties in information flow between intensive care units and GPs had been identified before: lack of information about admission or discharge and ongoing needs of patients after an ICU stay and no involvement in treatment decisions were reported by GPs in other studies<sup>41-43</sup>. As valid data on the course of disease and current diagnoses and treatment is essential for follow-up, information during hospital stay and more detailed discharge information for GPs may be essential to enhance quality in after-care.

It has been shown that GPs lack information on sepsis and identification of post-ICU-complications<sup>28, 43</sup>. The acquisition of clinical knowledge has been described and explained by forming of "scripts" with repeated exposure to clinical patterns<sup>44</sup>. With no ongoing experience in handling ICU-patients and limited encounters of post-ICU patients, scripts related to the PICS cannot be expected to evolve in GPs in everyday practice. In our study, the educational intervention led to additional knowledge about specific long-term-post-ICU complications.

GPs appreciate personal discussion with experts as a valuable method of continuing education<sup>45</sup>, and outreach visits as a method to reach GPs have been used before and shown to be accepted well<sup>e</sup>. Knowledge gain has been demonstrated, but transfer to practice seemed to be difficult<sup>29, 46</sup>. Patient-related intervention may

be especially helpful<sup>29</sup> to facilitate knowledge transfer. In our study, GPs reported transfer to practice of the knowledge they acquired, which may be achieved by the patient-related education and the individual discussion of diagnosis and treatment in the practice.

Lack of continuum of care is a major patient concern after ICU discharge<sup>35, 36</sup>. This study demonstrates that GPs are familiar with their patients, know about their medical and psychosocial background and consider these aspects when caring for their patients. Therefore, GPs seem to be an appropriate ICU aftercare provider.

#### Limitations

Since 307 GPs were asked to take part in the trial, and 294 agreed, it is likely those who took part in the trial are presentative of other GPs in Germany<sup>33</sup>. Being involved into a sepsis aftercare trial makes GPs informants of the functioning of the RCTs intervention, but may have changes their perception of the post-sepsis patients they care for. They may have been more preoccupied with and focused on that patient than otherwise. It might be those who agreed to be interviewed were more interested than their peers in sepsis as 4 of the 18 GPs approached for interview declined. As only GPs in the urban area of Berlin were interviewed, specific aspects of GPs in rural settings may have been missed.

The interviews were fairly short, which may limit depth of insights. Time constraints are typical of GPs work and were mentioned repeatedly throughout the interview. As GPs are used to work when time is limited they managed to answer questions quickly and summon up their experiences.

#### Conclusion

GPs are capable in provision and coordination of ICU follow-up: They have a profound and holistic knowledge of these complex patients and can appreciate individual their impairments and residing symptoms. However, lack of specific knowledge about critical illness complications, and lack of information and communication with ICU care providers are barriers to optimal follow-up in primary care settings.

GPs should get the necessary background knowledge and individual background information of their patients to be able to provide high-quality care. Taking into account time constraints and preferred education formats, outreach visits in the context of the discharge of a post-ICU patient may be a valuable source of information and support in caring for patients for the GPs interviewed.

#### **Declarations**

Declarations of interest: none declared

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Ethics approval: The protocol of the SMOOTH-trial was approved by the institutional review board of the University of Jena, 26 January 2011 (No.3001/111). The protocol of this interview study was approved by the Ethics Committee of the Charité Universitätsmedizin April 2013 (No.EA4/023/13).

Author Statement: SGB, KS and CH had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. Study concept and design: SGB, CH, JG, KS.

Outreach training conduction: KS. Aquisition, analysis of data: SGB. Interpretation of data: SGB, CH, KS, JG, KT. Drafting of the manuscript: SGB, KS, KT. Critical revision of the manuscript for important intellectual content: SGB, CH, KS, JG, KT.

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# **Tables**

**Table 1: Coding framework** 

# A: Caring for post-sepsis patients

Themes	subthemes
Profound knowledge of	Pre-existing disease
patients	Personality
	Illness behaviour
	Social background
	Continuity of care
Lack of information	
Emotional involvement	
Individual appraisal of	General weakness and limited functioning
persisting symptoms	Alteration to pre-sepsis condition
	Specific diagnosis of common complications after intensive care
	Individual complication

# B: Experience and acceptance of the outreach education

Themes	subthemes
Time and effort	Convenience by outreach visit
	Time strains, competing tasks
Knowledge	Persisting elevated mortality after discharge
	Specific long-term complications
	(Polyneuropathy, post-traumatic distress)
	(1 oryneuropathy, post-traumatic distress)
	Relevant summary for practice
Implementation in	Identifying complications
practice	Initiation of specific therapy
	Low relevance as small patient numbers in practice

### Table 2: Characteristics of participating GPs and patients

#### A: Characteristics of the interviewed GPs (n)

Total Male Female 

Age [years] 41-64 (mean: 54) Working in Practice [years] 9-33 (mean: 19)

#### B: Characteristics of post sepsis patients cared for by the GPs (n)

(patients included in the RCT)

Total Male Female

Age [years] 45-82 (mean: 66)

Sepsis focus 3 pulmonal

2 gastrointestinal

3 renal

3 renal
3 tissue infection
3 unknown

Table 4: Quotations: Caring for patients after critical illness.

Themes and subthemes	Quotation
Patients	
Previous health status	"Well, he was a spry patient, he bore his age well and he had no relevant preexisting disease () and he came mainly for check-ups." GP 9
	"Yes, she needed home visits before. She had an insulin-dependent diabetes, COPD, an heavy nicotine abuse she gave up after a hospital admission, we had home oxygen therapy before, there was a problem with alcohol meanwhile, she had skin problems, heart failure, high blood pressure, all that existed before." GP 5
	"A young man, I know him since his school times, over time he developed arterial hypertension. It is obviously in the family, as both his parents suffered from it and a chronic gastritis, apart from this no abnormalities." GP 3
	"I didn't have much contact to (him) before, because he was comparatively fit for his age. He predominantly had orthopedic problems. He is still active, playing golf and so on and () but internal diseases, that were serious, he didn't have that" GP 8
Personality and illness behaviour	"She was actually- or she is actually a very modest and shy person and for her medical problems she only claimed what she really needed urgently at that moment. A very kind and pleasant patient." GP 12
	"(she is a) tall and robust woman, with a croaky voicea heavy smoker, always unhappy. Niggling, unsatisfied and complaining, but also a fighter." GP 6
	"but she always was…she was a though woman and she never liked taking pills and she eventually said, it is too much, she can't take it and she got used to the symptoms and she would like to take smaller doses (), she preferred to be without pills." GP 5
	"well, a rather moaning patient, that came with all kinds of ailments and I considered him generally to be healthier than he himself did. " GP7
Social background	"She had a quite young daughter. Despite being my age, she had a young daughter and I think that's why she needed to be functioning and go back to work and she needed the money, yes." GP 6
	"he himself less, but his wife is quite depressive and that means eventually one has problems in everyday life." GP 8
	"I know the whole family (…) I know him only since about ten years but the rest of the family more than 30 years (…). They are all very scientific, that's what I would say. His wife is in a high position in the administration of veterinary surgeons (…), the son is biologist and works in science and the other daughter is a psychologist." GP 10
	"she had a comparatively young daughter, despite being my age, she has a young daughter and I think that's why she was in need to come

back to normal and	l go working and she nee	ded the money." GP 6
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New patient

"Well, I basically got to know Mr. (...) only as an acute patient after the hospital admission. He looked for a new GP after this adverse fate happened to him." GP 2

#### Critical illness

Lack of information

"The event of sepsis itself, as I said, wasn't diagnosed by me, in the practice, but happened in hospital after the operation and that's why I sort of got him back here as everything was finished. I just had to sort of accept that (…) in the end, I didn't have much to do with it and that's why I don't know much about it." GP8

"I only saw him again after rehabilitation, I didn't get a discharge letter either. I only got notice of these things as he stood here in front of me." GP 4

**Emotional** impact

"This was a very unlucky course of events (...) surely, everybody asks, 'why is it just me?" GP 3

"I once visited him in hospital and was shocked (...) well, this was a dramatic story." GP 10

#### Health status

General weakness and ow functioning

"Well, she was a shadow of her former self." GP 6

"...he is not up and about again. Well, he can't leave the flat, he walks short distances like to the toilet, from bed to toilet, from bed to living room" GP 11

"I have visited him once in the hospital and was shocked. He could only talk slowly, maybe in an orderly way, but he was heavily impaired after this intensive care therapy. And afterwards, it got better, he became clearer from the cerebral point of view and the slowing, that was extreme, went away." GP 10

"...in the beginning, she needed house visits, well, I can only see that her health condition only improved very slowly over a long period of time. That's all I can say about it." GP 12

Alteration to pre-sepsis condition

"...but, I must say, (he) had some problems with his peripheral nerves before due to his lifestyle, (due to) alcohol (..). There was some damage before and then, with the sepsis, that only came to the point it became clinically apparent and now that is the situation." GP 2

"...just like before, she has from time to time exacerbations of her COPD." GP 12

"...he had depression before and had depression afterwards and I believe his depression was even less, (...) He had a longstanding depression so you can't put these things (sepsis) forward." GP 10

"...basically, he kept all the diseases he had before and everything grew gradually worse." GP 11

Specific diagnosis of common complications after intensive care

"...he had this critical illness neuropathy with pains and muscle weakness and at the beginning also psychological problems with insomnia."

GP 1

"...now (she suffers from) increasing polyneuropathic pain, that needs to be treated with strong pain killers, with opioids." GP 2

"...well, he still has a post traumatic distress syndrome, he is still looking for a psychologist." GP 4

"...he is impaired a bit by the polyneuropathy." GP 9

Individual complication

"...because she had, she lost her leg with the sepsis and she, she had an amputation and before she could move about and could leave the apartment. But, afterwards, not anymore because she couldn't manage the stairs with one leg." GP5

"...and then she was depressive because she had the colostomy." GP 6

Table 5: Themes, subthemes and quotations impact of outreach education.

Themes and subthemes	Quotation
Acceptability	
Convenience	"I was approached at a time, I had time and as we arranged it, that was ideal (…) it was announced early enough and I got a mail-reminder an I didn't have to move anywhere, that could happen here, well, the colleague was really committed (…) I would say that was ideal." GP 2
	"well, that (the outreach education) happened here in the practicenice and friendly adapted to the needs of the doctor very good, that was comfortable. Didn't burden me much either." GP 6
Time strains, competing tasks	"well, it was really very interesting, the training, but this is – like today (the interview) – just one more thing, that delays and I would rather e.g. go for lunch or something else." GP 11
	"We have two thousand patients, work has grown so intense, that one has to leave out everything that is not absolutely necessary." GP 12
Impact on knowledge	
Persisting elevated mortality after discharge	"The mortality after discharge, () , that was very impressive, well, because I thought: sepsis overcome, well, everything is fine and the bird flies on." GP 2
	"that statistic, that said, ok, patients that survived this have a much higher mortality () these numbers were quite alarming." GP 5
Specific long-term complications	"well, that was mainly new, that one looks at sepsis as a complex illness with long-term complications. I did look at is more as a complication, that, when cured, is presumably good and done with." GP 11
	"the most helpful was, as I said, the connection. Generally with sepsis, that sepsis can cause other diseases () it seems, sepsis can cause serious alterations in the peripheral nerves." GP 2
	"the fact, that polyneuropathy had a connection to sepsis was not known to me at all." GP 12
Relevant summary for practice	"we all have learnt that during medical studies, but it is notone doesn't meet a sepsis survivor every day. It is not everyday business. And that's why I found it interesting, that you had it explained again." GP 5
	"in continuing education, we don't get the things that are relevant for practice enough, in that way, it was a nice, short update and training, but nothing really new." GP 8
Diagnosis of sepsis	what kind of symptoms, how sepsis manifests itself, because, one doesn't consider it so much, isn't it?" GP 6

#### Transfer to practice

Identifying complications

"...and since then, I turn my attention more to those symptoms, (...) I really pay attention to things now, that I didn't consider before. It really helped me." GP 6

"One is sensitized for it. Yes, I now pay more attention, especially regarding polyneuropathy and so on, I watch more closely, I say, ok, be careful, here you must consider that, that is a case you must watch out and ask, if she doesn't tell herself, whether she has symptoms." GP 5

Initiation of specific therapy

"...now, I would always look first, that I talk with him about what he went through and how it felt in the hospital, what impressions, what experiences, what feelings and that one really goes on to arrange for psychological care more quickly." GP 4

"...and I also did some of that in practice, I mentioned the referral to a psychologist and that became very clear." GP 4

"...from that training I learnt, that it makes sense, to send the patient to physiotherapy. That it is not only about medication, his usual medication and putting it - may be a bit trivial- I would prescribe antidepressants as well." GP 7

Diagnosis of sepsis

"...(reporting a case of postoperative sepsis) and I really was more careful and said, this lady has a sepsis. (...) I now have an eye on these symptoms and I refer more quickly." GP 6

Low relevance

"I don't have any patients after sepsis, that's why I can't change what I am doing." GP 3

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Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

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Title			
	<u>#1</u>	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	7
Abstract			
	<u>#2</u>	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Introduction			
Problem formulation	<u>#3</u>	Description and significance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	5

Purpose or research question	<u>#4</u>	Purpose of the study and specific objectives or questions	6
Methods			
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Data collection instruments and technologies	<u>#11</u>	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	7
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Links to empirical data	<u>#17</u>	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	24-28
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	<u>#18</u>	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	13,14
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Limitations	<u>#19</u>	Trustworthiness and limitations of findings	14
Other			
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Funding	<u>#21</u>	Sources of funding and other support; role of funders in data collection, interpretation and reporting	15

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# **BMJ Open**

# General practitioners' views and experiences in caring for patients after sepsis - a qualitative interview study

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# General practitioners' views and experiences in caring for patients after sepsis

# - a qualitative interview study

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## Abstract

## Rationale

Patients surviving critical illnesses, such as sepsis, often suffer from long-term complications. After discharge from hospital, most patients are treated in primary care. Little is known how general practitioners (GPs) perform critical illness aftercare and how it can be improved. Within a randomized controlled trial, an outreach training programme has been developed and applied.

# **Objectives**

The aim of this study is to describe GPs' views and experiences of caring for post-sepsis patients and of participating a specific outreach training.

# Design

Semi-structured qualitative interviews

# Setting

- 14 Family practices in the metropolitan area of Berlin, Germany
- 14 GPs, who had participated in a structured sepsis aftercare program in primary care

## Results

Themes identified in sepsis aftercare were: Continuity of care and good relationship with patients, GP's experiences during critical illness and impact of persisting symptoms. An outreach education as part of the intervention was considered by the GPs to be acceptable, helpful to improve knowledge of the management of post-intensive care complications and useful for sepsis aftercare in daily practice.

# **Conclusions**

GPs provide continuity of care to patients surviving sepsis. Better communication at the ICU-GP interface and training in management of long-term complications of sepsis may be helpful to improve sepsis aftercare.

**Keywords:** post intensive care syndrome, sepsis, primary care, General Practitioner, aftercare, outreacheducation, qualitative research

## **Abbreviations**

GP: general practitioner

ICU: intensive care unit

PICS: Post-intensive care syndrome

SMOOTH: Sepsis survivors monitoring and coordination in outpatient health care

Word count abstract: 201

Word count manuscript: 4271

# Strengths and limitations of this study

- This is the first study to explore in detail GPs' views of managing sepsis survivors.
- Using qualitative interviews meant GPs could raise issues that were salient to them.
- Some of the interviews were short due to GPs having limited time to take part.
- Only GPs in one metropolitan area were interviewed.



# **Introduction**

An increasing number of patients are treated in intensive care units (ICUs) and survive a critical illness such as sepsis<sup>1</sup>. After discharge, patients may suffer from long-term consequences<sup>2</sup>, such as critical-illness-polyneuropathy, critical-illness-myopathy, cognitive decline, chronic pain<sup>3-6</sup>, depression or post-traumatic stress disorder<sup>3 7 8</sup>. These sequelae are referred to as the "Post-intensive care syndrome" (PICS)<sup>1</sup>. They result in lower health-related quality of life and elevated mortality rates, as well as increased health care use<sup>9-11</sup>.

International guidelines state that patients with PICS should have ongoing, long-term monitoring and therapy<sup>12 13</sup>. Some patients discharged from ICUs are referred to ICU follow-up clinics. The purpose and structure of these clinics vary between countries, but change of clinical outcomes are rarely shown<sup>14-17</sup>. In addition, continuity of care at an ICU-follow up clinic may be difficult, when the patient lives far from the ICU and needs frequent follow-up<sup>18-20</sup>. Even if intensive care doctors and nurses are familiar with complications after critical illness, their role in coordinating ICU follow-up is discussed controversially<sup>17 21</sup>: They seem not to be trained in outpatient care coordination and the clinical variety of possible post-ICU complications<sup>17</sup>. Additionally, they do not know their patients for long and therefore may lack insight into the patient's psychosocial background<sup>22</sup>. On the contrary, GPs have a long-lasting relationship with their patients and provide care coordination as a core task<sup>23</sup>, which is highly appreciated by the patients<sup>24</sup>. This makes GPs ideal advocates of patients in their rehabilitation pathways. Thus, a Dutch retrospective cohort study found an increased consultation rate in primary care following ICU discharge<sup>25</sup>. Considering, that there were more than two million intensive care treatment cases just in Germany in 2017<sup>26</sup> and an assumed increase driven by the Covid-19 pandemic<sup>27</sup>, GPs need to know how to provide best post-intensive care to these patients, as it has been already called for by others<sup>28</sup>. The concept of the PICS is quite recent, but GPs intensive care experiences may date back to medical studies or early hospital rotations. In a qualitative study, GPs reported lack of background knowledge and confidence in diagnosing and treating post sepsis complications<sup>29</sup>. Kahn (2007) states that GPs need to be educated in how to care for patients after critical illness but do not provide suggestions about how this should be done<sup>22</sup>.

Outreach education delivered by academics to the GPs appeared to change their clinical behavior and improve patient care.<sup>30</sup> However, current evidence mainly focuses on changing prescribing patterns rather than on complex treatment strategies. Educational outreach visits providing knowledge to primary care for relatively

rare medical problems are shown to enhance confidence<sup>31</sup> and are acceptable to GPs<sup>32</sup>. Such an intervention may be effective in educating GPs in how to effectively care for patients with PICS. However, whether it is needs to be assessed.

The SMOOTH trial evaluated a structured after-care program in general practice for sepsis survivors including an outreach education for GPs<sup>33 34</sup>. Sepsis is one of the leading causes of long-term-ICU stays and can be viewed as a model illness for critical disease<sup>35</sup>. The intervention evaluated in the trial was designed with reference to the Chronic Care Model<sup>36</sup> at the level of a GP practice. It is focused on patient empowerment, a proactive care team and case management to ensure continuity of care. The trial did not find an improvement in mental health–related quality of life at 6 months after ICU discharge compared to usual care<sup>33 34</sup>. As part of this trial, in-depth interviews were held with GPs to explore their experiences with patients discharged from ICU and the intervention. Qualitative research has been conducted with post-ICU patients in detail<sup>37-43</sup>, but, to date, no one had explored in depth the views and experiences of GPs caring for these patients. The aim of this study is to describe GPs' views and experiences of caring for post-sepsis patients and of participating a specific outreach training, in order to inform and contribute to applicable future aftercare structures in primary care.

# Methods

# The SMOOTH-trial

The SMOOTH trial is a multi-center RCT evaluating a primary-care based aftercare-intervention for sepsis survivors. The intervention included monitoring of the patient by a case manager (a specialized nurse), a patient education session delivered by the case manager and an educational outreach-visit by a liaison physician to the GP, details are reported elsewhere<sup>33</sup>. Patients were recruited in the ICU and when they agreed to participate, their GPs were contacted and asked to join also the trial. Two hundred and nineteen patients agreed to participate, with 148 patients were randomized to the intervention and 143 patients to the control group receiving usual care. As some patients changed their GPs during the trial, the number of GPs was slightly larger than the number of patients. Three hundred seven GPs were approached to participate. Two hundred and ninety-four (95.8%) agreed and were included in the trial. Of total 159 GPs in the intervention group, 55 were recruited at the Berlin trial site.

The intervention directed at the GP consisted of one outreach educational visit by a liaison physician - a GP trained in sepsis aftercare. The visit was scheduled after the patient's discharge and according to time

preferences of the GPs. It took place in the GP practice and lasted about one hour. The education session included a brief overview of sepsis epidemiology and diagnosis, including red flags in primary care, but focused specifically on the six most common sequelae of sepsis ("Sepsis Six"). The epidemiology of long-term sequelae, practical tools for diagnoses and monitoring, as well as evidence-based therapeutic options in routine outpatient care were presented. A detailed manual covering all the information given and a brief sepsis pocket-card summarizing main points for everyday practice were handed over to the GP, published elsewhere<sup>34</sup>. The GP was asked to contact the liaison physician later at any moment in the study if questions arose during follow-up of the patient.

# Study design and data collection

As part of implementation evaluation, semi-structured interviews were held with the GPs in the intervention group of the RCTs to gain insight into their experiences caring for patients surviving sepsis and the GP education that had been delivered as part of the intervention.

Qualitative methods are applied within the research paradigm of critical realism to complete the results of the quantitative evaluation using a qualitative exploration<sup>44</sup>. Critical realism can be used to understand the complexities in primary care and events and phenomena in this setting<sup>45</sup>. The aim was to illuminate and understand the functioning of the intervention in the social background of a GP practice and to extract suggestions for future and optimized aftercare in General Practice.

The research team consisted of a 4th year medical student (NS), who conducted the interviews as part of a research project, and four academic GPs (SGB, CH, KS, JG) who were involved in analyses of the data. NS had received training in qualitative research interviews and was regularly supervised throughout the study by SGB and CH, who are experienced qualitative researchers. NS had not been involved in the SMOOTH trial, and interviewees were informed of this, to ensure they felt comfortable making any negative comments about the trial. SGB, CH, KS and JG were involved in the trial. At the time of the interviews they were not aware, that the outreach education did not change patient's mental health related quality of life (primary outcome).

A topic guide was developed and based on the aims of the study and an understanding of relevant literature.

The questions included focused on the GPs' experiences of caring for patients who had survived sepsis, and their experiences of the trial intervention.

We purposefully sampled GPs for interview to ensure interviews were held with GPs of varying gender and duration of work experience. All those approached for interview had worked at the Berlin trial site. If GPs were willing to be interviewed, they were mailed information about the interviews and a consent form. GPs willing to be interviewed could stipulate the time and location of their interview. The first interview was used as a pilot but as no changes were made to the topic guide, this interview was included in the analysis. With participant consent, the interviews were audiotaped and transcribed verbatim by NS. GPs were interviewed until data saturation was reached, i.e. when no new themes were identified in the later interviews.

# **Patient and Public Involvement**

Patient's perspectives and needs were included into topic guide development by the study team. Beside literature research, it was based on the results of qualitative interviews with sepsis survivors, using the same methodical approach and being published elsewhere<sup>42</sup>.

# Data analysis

The interviews were analyzed thematically<sup>46</sup>. Inductive thematic coding was used to gain an overall insight into the perspectives of the GPs. Transcripts of four interviews were read and re-read by different members of the research team (SGB, CH, KS, JG) who identified themes and developed initial coding frames. These researchers repeatedly discussed their codes and interpretation of the data. Once the coding frames had been agreed, they were applied to all interviews, see Tables 1 A and B. Coding was done manually by SGB. Results were presented to the research team and discussed until consensus was reached (SGB, CH, JG, KS).

This study refers to the standards for reporting qualitative research (SRQR).<sup>47</sup>

# Results

# **Participants**

We contacted 18 GPs for interview. Four GPs declined to participate due to lack of time. The 14 GPs who agreed to be interviewed (Table 2) choose to be interviewed at work, on practice premises, in a private room. Details of the patients the GPs cared for are shown in Table 3. After 14 interviews, theoretical saturation was reached with no new aspects emerging in the last two interviews. The interviews were conducted from January to August 2013 and lasted 12–28 minutes (mean 20 minutes). Themes considered relevant to this paper with corresponding quotes are shown in Tables 4 and 5.

# Caring for patients after critical illness

When analyzing the GPs' accounts, three main themes related to their experience of caring for patients after intensive care were identified as continuity of care and good relationship with patients, GP's experiences during critical illness and impact of persisting symptoms after discharge.

# Continuity of care and good relationship with patients

At the start of the interview, the GPs were asked to talk freely about their patient. The accounts given suggested that specific medical diagnoses and the acute sepsis diagnosis played a limited role in the GPs' narration. GPs often commented on the patient's condition before they were diagnosed with sepsis, discussing their pre-existing disease and previous general health status. It was evident that many of them were familiar with the patients' medical history.

Many GPs also talked about the patient's personality. They often focused on the patient's coping and illness behavior as one GP explained:

"... she is actually a very modest... and shy person and for her medical problems she only claimed what she really needed urgently at that moment. A very kind and pleasant patient." GP 12

Some GPs also reported on the personal and employment situation of their patients, especially if they felt that this had been important to the recovery of the patient:

"Despite being my age, she had a young daughter and I think that's why she needed to be functioning and go back to work and she needed the money, yes." GP 6

Even if most GPs seemed to know their patients very well, two GPs stated that they started caring for their patients only after the sepsis hospital stay. These two GPs gave little information about their patients.

# GP's experiences during critical illness

Most GPs commented that they lacked information about the acute sepsis event. They had not been informed about their patient's condition or involved in any of the treatment decisions made whilst their patient was in hospital. Several GPs could not specify the exact diagnosis and focus of the sepsis.

"The event of sepsis itself, as I said, wasn't diagnosed by me, in the practice, but happened in hospital after the operation and that's why I sort of got him back here as everything was finished. I just had to sort of accept that (...) in the end, I didn't have much to do with it and that's why I don't know much about it. "GP 8

Some GPs perceived the acute sepsis event as a tragic lifetime event for their patients and discussed the emotional impact of the serious impact on the patient and his/her family.

"This was a very unlucky course of events (...) surely, everybody asks, why is it just me?" GP 3

# Impact of persisting symptoms

GPs mentioned a number of different aspects when they described the condition of their patients after discharge and the impact of sepsis sequelae in their quality of life: general weakness and low functioning, the impact of preexisting diseases, individual specific health impairments and – less frequently- specific diagnosis of long-term-complications contributing to PICS.

Many interviewees described a general weakness and low functioning of their patients. They attributed this to the severe illness and the long hospital stay, without specifying the factors and causes contributing to the weakness like underlying illnesses, specific complications or treatment side effects. The focus of their reports was on the consequences for independence and autonomy of their patients rather than underlying pathomechanisms.

"Well, she was a shadow of her former self" GP 6

Many GPs compared their patients' health status to their condition before critical illness. In some cases, they saw their patients' impairment after discharge as, at least in part, attributable to pre-existing and chronic illness. In their perception, the acute sepsis event did not alter status of these patients much.

"Essentially, he kept the diseases he had before and everything got gradually a bit worse. He tended to be depressive before and now it isn't much worse." GP 11

The report about their patient condition and complications after sepsis was in many cases given in common, everyday language without listing specific medical diagnoses or specific sepsis complication. They rather concentrated on reporting on everyday functioning and overall well-being. Only some GPs classified specific sepsis sequelae and precisely stated these diagnoses. Some added being only aware of the diagnosis after the education session, they received as part of the study intervention.

"And mainly... he was quite distressed by the gait disturbance; by the painful paresthesia he had (...) the polyneuropathy was what was left from the sepsis syndrome." GP 8

Some GPs reported individual complications of sepsis or sepsis therapy had the main impact on the patient's quality of life afterwards, e.g. the loss of a limb or a persisting colostomy.

"As she had, because of this sepsis, she basically lost the leg, well, she had an amputation and ...hmm...she was still quite mobile before and could leave the flat. Hmm, afterwards no longer, because with one leg she couldn't manage the stairs." GP 5

One GP could not contribute to that aspect, as his patient died shortly after discharge.

# Impact of the outreach education

Three main themes that described the impact of the education session were identified: acceptability, improvement of knowledge, and the transfer to professional practice.

# Acceptability

Most participants stated that they appreciated the time and the effort on the side of the liaison physician to come to their premises and adapt to their schedule. They commented that this was an advantage for their own time schedule and comfort.

"I was approached at a time that was convenient for me (...), I didn't need to move anywhere, that could happen here, well, the colleague bothered to come (...) and as I said that was ideal, I would say." GP 2

However, some GPs said they had many patients to care for and tasks to cope with and could not spare any time for the training. A few also mentioned that post sepsis patients are rare in a GP practice and that they would rather save time in continuing education for more common diseases.

"Well, it was very interesting, the education, but this is just another additional point, that takes time and I would prefer e.g. to have lunch or something similar." GP 11

# Improvement of knowledge

The majority of practitioners stated that they had gained new knowledge from the education. Many interviewees reported it was new to them that sepsis can cause specific disease sequelae into after hospital discharge.

"Yes, that was largely new to me, that sepsis is seen as a complex illness with long lasting complications.

Till now, I saw it more as a complication, that, when cured, is resolved." GP 11

GPs often also stated, that they weren't aware that mortality is still elevated long-term after discharge until they heard about that in the education session.

"Most helpful was (...) that sepsis e.g. has a high mortality, the numbers were alarming! I mean, the mortality after discharge, (...) basically, I thought: Sepsis survived, ok, the bird flies on." GP 2

Some of the GPs reported that they did not know before that polyneuropathy and psychological problems were common consequences after sepsis and intensive care.

"I think, I would not have seen the connection before. Because she had so many other reasons for a polyneuropathy, I would have probably linked it to the diabetes." GP 5

One GP acquired more information about diagnosis of a sepsis in a patient, even though that was not in the focus of the education session.

Some GPs stated that they already knew the information given to them, but even when this was the case, they still appreciated the repetition and summary preparing them for the care of the patient.

"Well, I didn't find anything really new to me. But it was brought back and I did concentrate on it and looked closer to it. That was new to me and helps me for, well, aftercare." GP 9

One doctor saw no benefit from the education; he had done research in this field before his GP work and had the relevant knowledge before.

# Transfer to practice

Most of the GPs interviewed said that the new information helped them care for the patient included in the trial, and that it would help them in their future work with similar patients. Most of them saw a benefit in identifying sepsis sequelae.

"...mainly the polyneuropathy and so on, I look out for it more closely. I say to myself: Look out! You must keep that in mind and ask for it, when they don't tell on their own, if they have problems." GP 5

Some reported consequences for the therapy of the patient they cared for within the study and some stated that they would probably change their therapeutic approach to similar patients in the future.

"I believe I changed some things afterwards. I mentioned the psychotherapist afterwards, that became quite clear, and (patient's name) did agree to that." GP 4

One GP had quickly diagnosed a patient with acute sepsis since the training, even though diagnosis of sepsis was not its main focus.

Some GPs doubted the relevance of the information for their work. They stated that caring for similar patients was a very rare event in their practice, and therefore they did not think they would apply the knowledge they had learnt.

"I don't have any sepsis patients - that's why I can't change anything about what I do." GP 3

# **Discussion**

Findings from this study suggest that GPs provide continuity of care and a good relationship with patients and consider pre-existing and chronic disease, personality and coping patterns, as well as social background, when providing post-ICU-care to patients. Many interviewees described the long-term impact of sepsis on their patients as a general weakness and malfunctioning and considered it in relation to the patient's pre-sepsis constitution. Some GPs expressed empathy with the serious life event their patient experienced. GPs reported a lack of information about the course of the disease and their patient's condition while they were in the hospital. Diagnosing and listing specific sepsis sequelae played a minor role.

The outreach education session was acceptable to most GPs. Most GPs acquired new information about long-term-complications of sepsis. They considered this information as helpful to identify and start treatment for specific post-sepsis symptoms. This finding is consistent with findings from a recent qualitative study critical care nurses delivering a recovery programme to ICU survivors<sup>48</sup>. However, some GPs did not value it and pointed to the small numbers of post-sepsis-patients being in competition with other patients and tasks.

While most of the GPs' accounts suggested a long-standing knowledge of the patient and an individual appraisal of their health impairments after discharge, they lacked detailed medical knowledge about sepsis complications. The outreach education was mainly well accepted and seemed to provide a valid setting to improve knowledge about specific diagnostic and therapeutic concepts GPs can apply in their professional practice.

# Comparison with existing literature

 studies<sup>43</sup>. A wide range of ongoing health impairments was identified and loss of autonomy was a main aspect<sup>37</sup>-<sup>39</sup>. The views of the GPs identified here is very close to patients' perspectives. The GPs also reported general weakness and low functioning as a main aspect and a very individual apprehension of complaints and

Patients' perceptions of their quality of life after an ICU-stay have been examined in several qualitative

impairment. This congruence may facilitate a patient-centered after-care especially in a primary care setting.

Difficulties in information flow between intensive care units and GPs had been identified before: lack of

information about admission or discharge and ongoing needs of patients after an ICU stay and no involvement in

treatment decisions were reported by GPs in other studies<sup>49-51</sup>. As valid data on the course of disease and current

diagnoses and treatment is essential for follow-up, information during hospital stay and more detailed discharge

It has been shown that GPs lack information on sepsis and identification of post-ICU-complications<sup>29 51</sup>.

information for GPs may be essential to enhance quality in after-care.

The acquisition of clinical knowledge has been described and explained by forming of "scripts" with repeated exposure to clinical patterns<sup>52</sup>. With no ongoing experience in handling ICU-patients and limited encounters of

post-ICU patients, scripts related to the PICS cannot be expected to evolve in GPs in everyday practice. In our

study, the educational intervention led to additional knowledge about specific post-ICU complications. This may meet patient's ongoing need for feedback of their ICU history, as well as the resulting impairments<sup>43</sup>.

GPs appreciate personal discussion with experts as a valuable method of continuing education<sup>53</sup>, and outreach visits as a method to reach GPs have been used before and shown to be accepted well<sup>30</sup>. Knowledge gain has been demonstrated, but transfer to practice seemed to be difficult<sup>30 54</sup>. Patient-related intervention may be especially helpful<sup>30</sup> to facilitate knowledge transfer. In our study, GPs reported transfer to practice of the knowledge they acquired, which may be achieved by the patient-related education and the individual discussion of diagnosis and treatment in the practice.

Lack of continuum of care is a major patient concern after ICU discharge<sup>37, 38</sup>. The Chronic Care Model can be used to inform the ongoing care at the level of an individual practice, but also to organize patient-centered transsectoral and interdisciplinary care<sup>36</sup>. Local organization of a follow-up multiprofessional network and a stepped-care approach could help to ensure continuity of care. This study demonstrates that GPs are familiar with their patients, know about their medical and psychosocial background and consider these aspects when caring for their patients. Therefore, GPs seem to be appropriate ICU aftercare providers. In addition, increased intersectoral information flow could contribute to ensure continuity of care, e.g. quality of discharge letters may be improved by training, checklists, software solutions or positive peer pressure<sup>55, 56</sup>.

# Limitations

Since 307 GPs were asked to take part in the trial, and 294 agreed, it is likely those who took part in the trial are representative of other GPs in Germany<sup>34</sup>. Being involved in a sepsis aftercare trial informed GPs about the functioning of the RCTs intervention, but may have changed their perception of the post-sepsis patients they care for. They may have been more preoccupied with and focused on that patient than otherwise. It might be those who agreed to be interviewed were more interested than their peers in sepsis as 4 of the 18 GPs approached for interview declined. As only GPs in the urban area of Berlin were interviewed, specific aspects of GPs in rural settings may have been missed.

The interviews were fairly short, which may limit depth of insights. Time constraints are typical of GPs work and were mentioned repeatedly throughout the interview. As GPs are used to work under pressure, they were able to answer questions quickly and to summarise their experiences. Due to the time pressures they were

under, those interviewed were not contacted again to explore whether they agreed with the researchers' analysis of the data. However, themes and subthemes were discussed repeatedly in the research group.

# Conclusion

GPs are in a good position to offer continuity of care to sepsis survivors. However, they need training and information flow from secondary care for optimal aftercare provision.

GPs have a profound and holistic knowledge of these complex patients and can appreciate individual their impairments and residual symptoms. However, lack of specific knowledge about critical illness complications and lack of information and communication with ICU care providers are barriers to optimal follow-up in primary care settings.

GPs should get the necessary background knowledge and individual information of their patients to provide high-quality aftercare. Taking into account time constraints and preferred education formats, outreach visits in the context of discharge of a post-ICU patient may be a valuable source of information and support.

# **Declarations**

Declarations of interest: none declared

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Ethics approval: The protocol of the SMOOTH-trial was approved by the institutional review board of the University of Jena, 26 January 2011 (No.3001/111). The protocol of this interview study was approved by the Ethics Committee of the Charité Universitätsmedizin April 2013 (No.EA4/023/13).

<u>Author Statement:</u> SGB, KS and CH had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. Study concept and design: SGB, CH, JG, KS.

Outreach training conduction: KS. Acquisition, analysis of data: SGB. Interpretation of data: SGB, CH, KS, JG, KT. Drafting of the manuscript: SGB, KS, KT. Critical revision of the manuscript for important intellectual content: SGB, CH, KS, JG, KT.

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<u>Data sharing statement:</u> Audio recordings and transcriptions of the analysed interviews are stored at a secure server of Charité University Medicine and can be shared upon reasonable request.

The BMJ's qualitative reporting checklist has been created based on the reporting guidelines of standards for reporting qualitative research (SRQR).

# Table 1A

# Coding framework: Caring for patients after critical illness

Themes	Subthemes
Continuity of care and	Previous health status
good relationship with	
patients	Personality and illness behavior
•	Social background
	Continuity of care
GP's experiences during	Lack of information
critical illness	Emotional impact
Impact of persisting	General weakness and limited functioning
symptoms	Alteration to pre-sepsis condition
	Specific diagnosis of common complications after intensive care
	Individual complication

# Table 1B Coding framework: Impact of the outreach education

Themes	Subthemes
Acceptability	Convenience by outreach visit
	Time strains, competing tasks
Improvement of	Persisting elevated mortality after discharge
knowledge	Specific long-term complications (Polyneuropathy, post-traumatic distress)
	Diagnosis of sepsis
	Relevant summary for practice
Transfer into practice	Identifying complications
	Initiation of specific therapy
	Diagnosis of sepsis
	Low relevance as small patient numbers in practice

Table 2: Self-declared details of interviewed GPs

No. of GPs	Age*	Sex	practice organisation (no. of GPs)	license to practice since*	practice opening *	specialisation	practice characteristics, subspecialisations (multiple mention possible)	home visi (no/week)		patients > 60 years (estimate)	academic teaching practice
14	41-68 yrs (mean: 55 yrs)	8 male 6 female	6 joint practices (2-6 GPs) 8 single practices	<10 yrs: 0 10-20 yrs: 1 20-30 yrs: 3 30-40 yrs: 6 >40 yrs: 2 no data: 2	< 10 yrs: 1 10-20 yrs: 5 20-30 yrs: 4 30-40 yrs: 4 >40 yrs: 0 no data: 0	7 GPs 6 general internists# 1 practitioner without specialisation	2 none 7 complementary medicine 3 psychosomatics 2 pain management 1 gastroenterology 1 infectiology 1 oncology	<5/wk: 5-10/wk: >10wk: none: no data:	3 4 2 2 3	<30%: 5 30-50%: 6 >50%: 2	7 no 7 yes
							1 diabetology general internists.				

<sup>\*</sup>at the time of the interview

<sup>#</sup>a considerable proportion of primary care in Germany is provided by general internists.

Table 3: Characteristics of post-sepsis patients cared for by the GPs (n)

Total Male Female Age [years] 45-82 (mean 66) Sepsis focus 3 pulmonal 2 gastrointestinal 3 unknow. 3 renal

# Table 4: Quotations - Caring for patients after critical illness

# Themes and subthemes

## **Quotation**

# Continuity of care and good relationship with patients

# Previous health status

"Well, he was a spry patient, he bore his age well and he had no relevant preexisting disease (...) and he came mainly for check-ups." GP 9

"Yes, she needed home visits before. She had an insulin-dependent diabetes, COPD, an heavy nicotine abuse she gave up after a hospital admission, we had home oxygen therapy before, there was a problem with alcohol meanwhile, she had skin problems, heart failure, high blood pressure, all that existed before." GP 5

"A young man, I know him since his school times, over time he developed arterial hypertension. It is obviously in the family, as both his parents suffered from it and a chronic gastritis, apart from this no abnormalities." GP 3

"I didn't have much contact to (him) before, because he was comparatively fit for his age. He predominantly had orthopedic problems. He is still active, playing golf and so on and (..) but internal diseases, that were serious, he didn't have that." GP 8

# Personality and illness behavior

"She was actually- or she is actually a very modest... and shy person and for her medical problems she only claimed what she really needed urgently at that moment. A very kind and pleasant patient." GP 12

"...(she is a) tall and robust woman, with a croaky voice...a heavy smoker, always unhappy. Niggling, unsatisfied and complaining, but also a fighter." GP 6

"but she always was...she was a though woman and she never liked taking pills and she eventually said, it is too much, she can't take it and she got used to the symptoms and she would like to take smaller doses (..), she preferred to be without pills." GP 5

"...well, a rather moaning patient, that came with all kinds of ailments and I considered him generally to be healthier than he himself did. " GP7

# Social background

"She had a quite young daughter. Despite being my age, she had a young daughter and I think that's why she needed to be functioning and go back to work and she needed the money, yes." GP 6

,...he himself less, but his wife is quite depressive and that means eventually one has problems in everyday life." GP 8

"I know the whole family (...) I know him only since about ten years but the rest of the family more than 30 years (...). They are all very scientific, that's what I would say. His wife is in a high position in the administration of veterinary surgeons (...), the son is biologist and works in science and the other daughter is a psychologist." GP 10

"...she had a comparatively young daughter, despite being my age, she has a young daughter and I think that's why she was in need to come back to normal and go working and she needed the money." GP 6

## Continuity of care

"Well, I basically got to know Mr. (…) only as an acute patient after the hospital admission. He looked for a new GP after this adverse fate happened to him." GP 2

# GP's experiences during critical illness

Lack of information

"The event of sepsis itself, as I said, wasn't diagnosed by me, in the practice, but happened in hospital after the operation and that's why I sort of got him back here as everything was finished. I just had to sort of accept that (…) in the end, I didn't have much to do with it and that's why I don't know much about it." GP8

"I only saw him again after rehabilitation, I didn't get a discharge letter either. I only got notice of these things as he stood here in front of me." GP 4

**Emotional** impact

"This was a very unlucky course of events (...) surely, everybody asks, 'why is it just me?'" GP 3

"I once visited him in hospital and was shocked (…) well, this was a dramatic story." GP 10

# Impact of persisting symptoms

# General weakness and low functioning

"Well, she was a shadow of her former self." GP 6

"...he is not up and about again. Well, he can't leave the flat, he walks short distances like to the toilet, from bed to toilet, from bed to living room." GP 11

"I have visited him once in the hospital and was shocked. He could only talk slowly, maybe in an orderly way, but he was heavily impaired after this intensive care therapy. And afterwards, it got better, he became clearer from the cerebral point of view and the slowing, that was extreme, went away." GP 10

"...in the beginning, she needed house visits, well, I can only see that her health condition only improved very slowly over a long period of time. That's all I can say about it." GP 12

# Alteration to presepsis condition

"...but, I must say, (he) had some problems with his peripheral nerves before due to his lifestyle, (due to) alcohol (...) There was some damage before and then, with the sepsis, that only came to the point it became clinically apparent and now that is the situation." GP 2

"...just like before, she has from time to time exacerbations of her COPD." GP 12

"...he had depression before and had depression afterwards and I believe his depression was even less, (...) He had a longstanding depression so you can't put these things (sepsis) forward." GP 10

"...basically, he kept all the diseases he had before and everything grew gradually worse." GP 11

# Specific diagnosis of common complications after intensive care

"...he had this critical illness neuropathy with pains and muscle weakness and at the beginning also psychological problems with insomnia." GP 1

"...now (she suffers from) increasing polyneuropathic pain, that needs to be treated with strong pain killers, with opioids." GP 2

"...well, he still has a post traumatic distress syndrome, he is still looking for a psychologist." GP 4

"...he is impaired a bit by the polyneuropathy." GP 9

# Individual complication

"...because she had, she lost her leg with the sepsis and she, she had an amputation and before she could move about and could leave the apartment. But, afterwards, not anymore because she couldn't manage the stairs with one leg." GP5

....and then she was depressive because she had the colostomy." GP 6

# Table 5: Themes, subthemes and quotations: Impact of outreach education. Themes and Quotation subthemes Acceptability Convenience by "I was approached at a time, I had time and as we arranged it, that was ideal (...) it was announced early enough and I got a mail-reminder an I didn't have to move anywhere, outreach visit that could happen here, well, the colleague was really committed (...) I would say that was ideal." GP 2 "...well, that (the outreach education) happened here in the practice ...nice and friendly... adapted to the needs of the doctor... very good, that was comfortable. Didn't burden me much either." GP 6 ,,...well, it was really very interesting, the training, but this is – like today (the Time strains, competing tasks interview) – just one more thing, that delays and I would rather e.g. go for lunch or something else." GP 11 "We have two thousand patients, work has grown so intense, that one has to leave out everything that is not absolutely necessary." GP 12 Impact on knowledge Persisting elevated "The mortality after discharge, (...) that was very impressive, well, because I thought: mortality after sepsis overcome, well, everything is fine and the bird flies on." GP 2 discharge ,,...that statistic, that said, ok, patients that survived this have a much higher mortality (...) these numbers were quite alarming." GP 5 ,,...well, that was mainly new, that one looks at sepsis as a complex illness with long-Specific long-term complications term complications. I did look at is more as a complication, that, when cured, is presumably good and done with." GP 11 (Polyneuropathy, post-traumatic "...the most helpful was, as I said, the connection. Generally with sepsis, that sepsis distress) can cause other diseases (...) it seems, sepsis can cause serious alterations in the peripheral nerves." GP 2 ,...the fact, that polyneuropathy had a connection to sepsis was not known to me at all." GP 12 "...what kind of symptoms, how sepsis manifests itself, because, one doesn't consider Diagnosis of sepsis it so much, isn't it?" GP 6 Relevant summary for "...we all have learnt that during medical studies, but it is not...one doesn't meet a practice sepsis survivor every day. It is not everyday business. And that's why I found it interesting, that you had it explained again." GP 5 "...in continuing education, we don't get the things that are relevant for practice enough, in that way, it was a nice, short update and training, but nothing really new." GP 8 Transfer to practice "...and since then, I turn my attention more to those symptoms, (...) I really pay Identifying

complications

attention to things now, that I didn't consider before. It really helped me." GP 6

"One is sensitized for it. Yes, I now pay more attention, especially regarding polyneuropathy and so on, I watch more closely, I say, ok, be careful, here you must consider that, that is a case you must watch out and ask , if she doesn't tell herself, whether she has symptoms." GP 5

# Initiation of specific therapy

"...now, I would always look first, that I talk with him about what he went through and how it felt in the hospital, what impressions, what experiences, what feelings and that one really goes on to arrange for psychological care more quickly." GP 4

"...and I also did some of that in practice, I mentioned the referral to a psychologist and that became very clear." GP 4

"...from that training I learnt, that it makes sense, to send the patient to physiotherapy. That it is not only about medication, his usual medication and putting it - may be a bit trivial- I would prescribe antidepressants as well." GP 7

# Diagnosis of sepsis

"...(reporting a case of postoperative sepsis) and I really was more careful and said, this lady has a sepsis. (...) I now have an eye on these symptoms and I refer more quickly." GP 6

Low relevance as small patient numbers in practice

"I don't have any patients after sepsis, that's why I can't change what I am doing." GP 3

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# Reporting checklist for qualitative study.

Based on the SRQR guidelines.

# Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

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Page

Reporting Item

Number

Title

#1 Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended

# Abstract

#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions 

# Introduction

Problem formulation #3 Description and significance of the problem /

phenomenon studied: review of relevant theory and

empirical work; problem statement

Purpose or research #4 Purpose of the study and specific objectives or question question 6

# Methods

Qualitative approach and #5 Qualitative approach (e.g. ethnography, grounded research paradigm theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions

and limitations implicit in those choices and how those

choices influence study conclusions and transferability.

As appropriate the rationale for several items might be discussed together.

Researcher
characteristics and
reflexivity

#6

#9

Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability

Context

#7 Setting / site and salient contextual factors; rationale

Sampling strategy

#8 How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale

Ethical issues pertaining to human subjects

Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues

Data collection methods

#10 Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale

Data collection	<u>#11</u>	Description of instruments (e.g. interview guides,	7
instruments and		questionnaires) and devices (e.g. audio recorders)	
technologies		used for data collection; if / how the instruments(s)	
		changed over the course of the study	
Units of study	<u>#12</u>	Number and relevant characteristics of participants,	8
		documents, or events included in the study; level of	
		participation (could be reported in results)	
Data processing	<u>#13</u>	Methods for processing data prior to and during	7
		analysis, including transcription, data entry, data	
		management and security, verification of data integrity,	
		data coding, and anonymisation / deidentification of	
		excerpts	
Data analysis	<u>#14</u>	Process by which inferences, themes, etc. were	7,8
		identified and developed, including the researchers	
		involved in data analysis; usually references a specific	
		paradigm or approach; rationale	
Techniques to enhance	<u>#15</u>	Techniques to enhance trustworthiness and credibility	7,8
trustworthiness		of data analysis (e.g. member checking, audit trail,	
		triangulation); rationale	
Results/findings			

Syntheses and #16 Main findings (e.g. interpretations, inferences, and interpretation themes); might include development of a theory or model, or integration with prior research or theory

24-28

Links to empirical data #17 Evidence (e.g. quotes, field notes, text excerpts,

Zimo to ompinoar data	<u>// / / / / / / / / / / / / / / / / / /</u>	Evidence (e.g. quetes, neid netes, text execupte,	2 1 20
		photographs) to substantiate analytic findings	
Discussion			
Intergration with prior	<u>#18</u>	Short summary of main findings; explanation of how	13,14
work, implications,		findings and conclusions connect to, support, elaborate	
transferability and		on, or challenge conclusions of earlier scholarship;	
contribution(s) to the field		discussion of scope of application / generalizability;	
		identification of unique contributions(s) to scholarship	
		in a discipline or field	
Limitations	<u>#19</u>	Trustworthiness and limitations of findings	14
Other			
Conflicts of interest	<u>#20</u>	Potential sources of influence of perceived influence on	15
		study conduct and conclusions; how these were	
		managed	
Funding	<u>#21</u>	Sources of funding and other support; role of funders in	15
		data collection, interpretation and reporting	

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# **BMJ Open**

# General practitioners' views and experiences in caring for patients after sepsis - a qualitative interview study

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# General practitioners' views and experiences in caring for patients after sepsis

# - a qualitative interview study

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## Abstract

# **Background**

Patients surviving critical illnesses, such as sepsis, often suffer from long-term complications. After discharge from hospital, most patients are treated in primary care. Little is known how general practitioners (GPs) perform critical illness aftercare and how it can be improved. Within a randomized controlled trial, an outreach training programme has been developed and applied.

# **Objectives**

The aim of this study is to describe GPs' views and experiences of caring for post-sepsis patients and of participating a specific outreach training.

# Design

Semi-structured qualitative interviews.

# **Setting**

14 primary care practices in the metropolitan area of Berlin, Germany.

# **Participants**

14 GPs, who had participated in a structured sepsis aftercare program in primary care.

# Results

Themes identified in sepsis aftercare were: Continuity of care and good relationship with patients, GP's experiences during their patient's critical illness and impact of persisting symptoms. An outreach education as part of the intervention was considered by the GPs to be acceptable, helpful to improve knowledge of the management of post-intensive care complications and useful for sepsis aftercare in daily practice.

# Conclusions

GPs provide continuity of care to patients surviving sepsis. Better communication at the ICU-GP interface and training in management of long-term complications of sepsis may be helpful to improve sepsis aftercare.

**Keywords:** post intensive care syndrome, sepsis, primary care, General Practitioner, aftercare, outreacheducation, qualitative research

#### **Abbreviations**

GP: general practitioner

ICU: intensive care unit

PICS: Post-intensive care syndrome

SMOOTH: Sepsis survivors monitoring and coordination in outpatient health care

Word count abstract: 206

Word count manuscript: 4307

#### Strengths and limitations of this study

- This is the first study to explore in detail GPs' views of managing sepsis survivors.
- Using qualitative interviews meant GPs could raise issues that were salient to them.
- Some of the interviews were short due to GPs having limited time to take part.
  - Only GPs in one metropolitan area were interviewed.



# **Introduction**

An increasing number of patients are treated in intensive care units (ICUs) and survive a critical illness such as sepsis<sup>1</sup>. After discharge, patients may suffer from long-term consequences<sup>2</sup>, such as critical-illness-polyneuropathy, critical-illness-myopathy, cognitive decline, chronic pain<sup>3-6</sup>, depression or post-traumatic stress disorder<sup>3 7 8</sup>. These sequelae are referred to as the "Post-intensive care syndrome" (PICS)<sup>1</sup>. They result in lower health-related quality of life and elevated mortality rates, as well as increased health care use<sup>9-11</sup>.

International guidelines state that patients with PICS should have ongoing, long-term monitoring and therapy<sup>12 13</sup>. Some patients discharged from ICUs are referred to ICU follow-up clinics. The purpose and structure of these clinics vary between countries, but change of clinical outcomes are rarely shown<sup>14-17</sup>. In addition, continuity of care at an ICU-follow up clinic may be difficult, when the patient lives far from the ICU and needs frequent follow-up<sup>18-20</sup>. Even if intensive care doctors and nurses are familiar with complications after critical illness, their role in coordinating ICU follow-up is discussed controversially<sup>17 21</sup>: They seem not to be trained in outpatient care coordination and the clinical variety of possible post-ICU complications<sup>17</sup>. Additionally, they do not know their patients for long and therefore may lack insight into the patient's psychosocial background<sup>22</sup>. On the contrary, GPs have a long-lasting relationship with their patients and provide care coordination as a core task<sup>23</sup>, which is highly appreciated by the patients<sup>24</sup>. This makes GPs ideal advocates of patients in their rehabilitation pathways. Thus, a Dutch retrospective cohort study found an increased consultation rate in primary care following ICU discharge<sup>25</sup>. Considering, that there were more than two million intensive care treatment cases just in Germany in 2017<sup>26</sup> and an assumed increase driven by the Covid-19 pandemic<sup>27</sup>, GPs need to know how to provide best post-intensive care to these patients, as it has been already called for by others<sup>28</sup>. The concept of the PICS is quite recent, but GPs intensive care experiences may date back to medical studies or early hospital rotations. In a qualitative study, GPs reported lack of background knowledge and confidence in diagnosing and treating post sepsis complications<sup>29</sup>. Kahn (2007) states that GPs need to be educated in how to care for patients after critical illness but do not provide suggestions about how this should be done<sup>22</sup>.

Outreach education delivered by academics to the GPs appeared to change their clinical behavior and improve patient care.<sup>30</sup> However, current evidence mainly focuses on changing prescribing patterns rather than on complex treatment strategies. Educational outreach visits providing knowledge to primary care for relatively

rare medical problems are shown to enhance confidence<sup>31</sup> and are acceptable to GPs<sup>32</sup>. Such an intervention may be effective in educating GPs in how to effectively care for patients with PICS. However, whether it is needs to be assessed.

The SMOOTH trial evaluated a structured after-care program in general practice for sepsis survivors including an outreach education for GPs<sup>33 34</sup>. Sepsis is one of the leading causes of long-term-ICU stays and can be viewed as a model illness for critical disease<sup>35</sup>. The intervention evaluated in the trial was designed with reference to the Chronic Care Model<sup>36</sup> at the level of a GP practice. It is focused on patient empowerment, a proactive care team and case management to ensure continuity of care. The trial did not find an improvement in mental health–related quality of life at 6 months after ICU discharge compared to usual care<sup>33 34</sup>. As part of this trial, in-depth interviews were held with GPs to explore their experiences with patients discharged from ICU and the intervention. Qualitative research has been conducted with post-ICU patients in detail<sup>37-43</sup>, but, to date, no one had explored in depth the views and experiences of GPs caring for these patients. The aim of this study is to describe GPs' views and experiences of caring for post-sepsis patients and of participating a specific outreach training, in order to inform and contribute to applicable future aftercare structures in primary care.

### Methods

#### The SMOOTH-trial

The SMOOTH trial is a multi-center RCT evaluating a primary-care based aftercare-intervention for sepsis survivors. The intervention included monitoring of the patient by a case manager (a specialized nurse), a patient education session delivered by the case manager and an educational outreach-visit by a liaison physician to the GP, details are reported elsewhere<sup>33</sup>. Patients were recruited in the ICU and when they agreed to participate, their GPs were contacted and asked to join also the trial. Two hundred and ninety-one patients agreed to participate, with 148 patients were randomized to the intervention and 143 patients to the control group receiving usual care. As some patients changed their GPs during the trial, the number of GPs was slightly larger than the number of patients. Three hundred seven GPs were approached to participate. Two hundred and ninety-four (95.8%) agreed and were included in the trial. Of total 159 GPs in the intervention group, 55 were recruited at the Berlin trial site.

The intervention directed at the GP consisted of one outreach educational visit by a liaison physician - a GP trained in sepsis aftercare. The visit was scheduled after the patient's discharge and according to time

preferences of the GPs. It took place in the GP practice and lasted about one hour. The education session included a brief overview of sepsis epidemiology and diagnosis, including red flags in primary care, but focused specifically on the six most common sequelae of sepsis ("Sepsis Six"). The epidemiology of long-term sequelae, practical tools for diagnoses and monitoring, as well as evidence-based therapeutic options in routine outpatient care were presented. A detailed manual covering all the information given and a brief sepsis pocket-card summarizing main points for everyday practice were handed over to the GP, published elsewhere<sup>34</sup>. The GP was asked to contact the liaison physician later at any moment in the study if questions arose during follow-up of the patient.

### Study design and data collection

As part of implementation evaluation, semi-structured interviews were held with the GPs in the intervention group of the RCTs to gain insight into their experiences caring for patients surviving sepsis and the GP education that had been delivered as part of the intervention.

Qualitative methods are applied within the research paradigm of critical realism to complete the results of the quantitative evaluation using a qualitative exploration<sup>44</sup>. Critical realism can be used to understand the complexities in primary care and events and phenomena in this setting<sup>45</sup>. The aim was to illuminate and understand the functioning of the intervention in the social background of a GP practice and to extract suggestions for future and optimized aftercare in General Practice.

The research team consisted of a 4th year medical student (NS), who conducted the interviews as part of a research project, and four academic GPs (SGB, CH, KS, JG) who were involved in analyses of the data. NS had received training in qualitative research interviews and was regularly supervised throughout the study by SGB and CH, who are experienced qualitative researchers. NS had not been involved in the SMOOTH trial, and interviewees were informed of this, to ensure they felt comfortable making any negative comments about the trial. SGB, CH, KS and JG were involved in the trial. At the time of the interviews they were not aware, that the outreach education did not change patient's mental health related quality of life (primary outcome).

A topic guide was developed and based on the aims of the study and an understanding of relevant literature.

The questions included focused on the GPs' experiences of caring for patients who had survived sepsis, and their experiences of the trial intervention.

We purposefully sampled GPs for interview to ensure interviews were held with GPs of varying gender and duration of work experience. All those approached for interview had worked at the Berlin trial site. If GPs were willing to be interviewed, they were mailed information about the interviews and a consent form. GPs willing to be interviewed could stipulate the time and location of their interview. The first interview was used as a pilot but as no changes were made to the topic guide, this interview was included in the analysis. With participant consent, the interviews were audiotaped and transcribed verbatim by NS. GPs were interviewed until data saturation was reached, i.e. when no new themes were identified in the later interviews.

#### **Patient and Public Involvement**

Patient's perspectives and needs were included into topic guide development by the study team. Beside literature research, it was based on the results of qualitative interviews with sepsis survivors, using the same methodical approach and being published elsewhere<sup>42</sup>.

#### Data analysis

The interviews were analyzed thematically<sup>46</sup>. Inductive thematic coding was used to gain an overall insight into the perspectives of the GPs. Transcripts of four interviews were read and re-read by different members of the research team (SGB, CH, KS, JG) who identified themes and developed initial coding frames. These researchers repeatedly discussed their codes and interpretation of the data. Once the coding frames had been agreed, they were applied to all interviews, see Tables 1 A and B. Coding was done manually by SGB. Results were presented to the research team and discussed until consensus was reached (SGB, CH, JG, KS).

This study refers to the standards for reporting qualitative research (SRQR).<sup>47</sup>

# Results

#### **Participants**

We contacted 18 GPs for interview. Four GPs declined to participate due to lack of time. The 14 GPs who agreed to be interviewed (Table 2) choose to be interviewed at work, on practice premises, in a private room. Details of the patients the GPs cared for are shown in Table 3. After 14 interviews, theoretical saturation was reached with no new aspects emerging in the last two interviews. The interviews were conducted from January to August 2013 and lasted 12–28 minutes (mean 20 minutes). Themes considered relevant to this paper with corresponding quotes are shown in Tables 4 and 5.

# Caring for patients after critical illness

When analyzing the GPs' accounts, three main themes related to their experience of caring for patients after intensive care were identified as continuity of care and good relationship with patients, GP's experiences during their patient's critical illness and impact of persisting symptoms after discharge.

#### Continuity of care and good relationship with patients

At the start of the interview, the GPs were asked to talk freely about their patient. The accounts given suggested that specific medical diagnoses and the acute sepsis diagnosis played a limited role in the GPs' narration. GPs often commented on the patient's condition before they were diagnosed with sepsis, discussing their pre-existing disease and previous general health status. It was evident that many of them were familiar with the patients' medical history.

Many GPs also talked about the patient's personality. They often focused on the patient's coping and illness behavior as one GP explained:

"... she is actually a very modest... and shy person and for her medical problems she only claimed what she really needed urgently at that moment. A very kind and pleasant patient." GP 12

Some GPs also reported on the personal and employment situation of their patients, especially if they felt that this had been important to the recovery of the patient:

"Despite being my age, she had a young daughter and I think that's why she needed to be functioning and go back to work and she needed the money, yes." GP 6

Even if most GPs seemed to know their patients very well, two GPs stated that they started caring for their patients only after the sepsis hospital stay:

"Well, I basically got to know Mr. (...) only as an acute patient after the hospital admission. He looked for a new GP after this adverse fate happened to him."

These two GPs gave little information about their patients.

#### GP's experiences during their patient's critical illness

Most GPs commented that they lacked information about the acute sepsis event. They had not been informed about their patient's condition or involved in any of the treatment decisions made whilst their patient was in hospital. Several GPs could not specify the exact diagnosis and focus of the sepsis.

"The event of sepsis itself, as I said, wasn't diagnosed by me, in the practice, but happened in hospital after the operation and that's why I sort of got him back here as everything was finished. I just had to sort of accept that (...) in the end, I didn't have much to do with it and that's why I don't know much about it." GP 8

Some GPs perceived the acute sepsis event as a tragic lifetime event for their patients and discussed the emotional impact of the serious impact on the patient and his/her family.

"This was a very unlucky course of events (...) surely, everybody asks, why is it just me?" GP 3

# Impact of persisting symptoms

GPs mentioned a number of different aspects when they described the condition of their patients after discharge and the impact of sepsis sequelae in their quality of life: general weakness and low functioning, the impact of preexisting diseases, individual specific health impairments and – less frequently- specific diagnosis of long-term-complications contributing to PICS.

Many interviewees described a general weakness and low functioning of their patients. They attributed this to the severe illness and the long hospital stay, without specifying the factors and causes contributing to the weakness like underlying illnesses, specific complications or treatment side effects. The focus of their reports was on the consequences for independence and autonomy of their patients rather than underlying pathomechanisms.

"Well, she was a shadow of her former self" GP 6

Many GPs compared their patients' health status to their condition before critical illness. In some cases, they saw their patients' impairment after discharge as, at least in part, attributable to pre-existing and chronic illness. In their perception, the acute sepsis event did not alter status of these patients much.

"Essentially, he kept the diseases he had before and everything got gradually a bit worse. He tended to be depressive before and now it isn't much worse." GP 11

The report about their patient condition and complications after sepsis was in many cases given in common, everyday language without listing specific medical diagnoses or specific sepsis complication. They rather concentrated on reporting on everyday functioning and overall well-being. Only some GPs classified specific sepsis sequelae and precisely stated these diagnoses. Some added being only aware of the diagnosis after the education session, they received as part of the study intervention.

"And mainly... he was quite distressed by the gait disturbance; by the painful paresthesia he had (...) the polyneuropathy was what was left from the sepsis syndrome." GP 8

Some GPs reported individual complications of sepsis or sepsis therapy had the main impact on the patient's quality of life afterwards, e.g. the loss of a limb or a persisting colostomy.

"As she had, because of this sepsis, she basically lost the leg, well, she had an amputation and ...hmm...she was still quite mobile before and could leave the flat. Hmm, afterwards no longer, because with one leg she couldn't manage the stairs." GP 5

One GP could not contribute to that aspect, as his patient died shortly after discharge.

# Impact of the outreach education

Three main themes that described the impact of the education session were identified: acceptability, improvement of knowledge, and the transfer to professional practice.

#### Acceptability

Most participants stated that they appreciated the time and the effort on the side of the liaison physician to come to their premises and adapt to their schedule. They commented that this was an advantage for their own time schedule and comfort.

"I was approached at a time that was convenient for me (...), I didn't need to move anywhere, that could happen here, well, the colleague bothered to come (...) and as I said that was ideal, I would say." GP 2

However, some GPs said they had many patients to care for and tasks to cope with and could not spare any time for the training. A few also mentioned that post sepsis patients are rare in a GP practice and that they would rather save time in continuing education for more common diseases.

"Well, it was very interesting, the education, but this is just another additional point, that takes time and I would prefer e.g. to have lunch or something similar." GP 11

#### Improvement of knowledge

The majority of practitioners stated that they had gained new knowledge from the education. Many interviewees reported it was new to them that sepsis can cause specific disease sequelae into after hospital discharge.

"Yes, that was largely new to me, that sepsis is seen as a complex illness with long lasting complications.

Till now, I saw it more as a complication, that, when cured, is resolved." GP 11

GPs often also stated, that they weren't aware that mortality is still elevated long-term after discharge until they heard about that in the education session.

"Most helpful was (...) that sepsis e.g. has a high mortality, the numbers were alarming! I mean, the mortality after discharge, (...) basically, I thought: Sepsis survived, ok, the bird flies on." GP 2

Some of the GPs reported that they did not know before that polyneuropathy and psychological problems were common consequences after sepsis and intensive care.

"I think, I would not have seen the connection before. Because she had so many other reasons for a polyneuropathy, I would have probably linked it to the diabetes." GP 5

One GP acquired more information about diagnosis of a sepsis in a patient, even though that was not in the focus of the education session.

Some GPs stated that they already knew the information given to them, but even when this was the case, they still appreciated the repetition and summary preparing them for the care of the patient.

"Well, I didn't find anything really new to me. But it was brought back and I did concentrate on it and looked closer to it. That was new to me and helps me for, well, aftercare." GP 9

One doctor saw no benefit from the education; he had done research in this field before his GP work and had the relevant knowledge before.

# Transfer to practice

Most of the GPs interviewed said that the new information helped them care for the patient included in the trial, and that it would help them in their future work with similar patients. Most of them saw a benefit in identifying sepsis sequelae.

"...mainly the polyneuropathy and so on, I look out for it more closely. I say to myself: Look out! You must keep that in mind and ask for it, when they don't tell on their own, if they have problems." GP 5

Some reported consequences for the therapy of the patient they cared for within the study and some stated that they would probably change their therapeutic approach to similar patients in the future.

"I believe I changed some things afterwards. I mentioned the psychotherapist afterwards, that became quite clear, and (patient's name) did agree to that." GP 4

One GP had quickly diagnosed a patient with acute sepsis since the training, even though diagnosis of sepsis was not its main focus.

Some GPs doubted the relevance of the information for their work. They stated that caring for similar patients was a very rare event in their practice, and therefore they did not think they would apply the knowledge they had learnt.

"I don't have any sepsis patients - that's why I can't change anything about what I do." GP 3

#### **Discussion**

Findings from this study suggest that GPs provide continuity of care and a good relationship with patients and consider pre-existing and chronic disease, personality and coping patterns, as well as social background, when providing post-ICU-care to patients. Many interviewees described the long-term impact of sepsis on their patients as a general weakness and malfunctioning and considered it in relation to the patient's pre-sepsis constitution. Some GPs expressed empathy with the serious life event their patient experienced. GPs reported a lack of information about the course of the disease and their patient's condition while they were in the hospital. Diagnosing and listing specific sepsis sequelae played a minor role.

The outreach education session was acceptable to most GPs. Most GPs acquired new information about long-term-complications of sepsis. They considered this information as helpful to identify and start treatment for specific post-sepsis symptoms. This finding is consistent with findings from a recent qualitative study critical care nurses delivering a recovery programme to ICU survivors<sup>48</sup>. However, some GPs did not value it and pointed to the small numbers of post-sepsis-patients being in competition with other patients and tasks.

While most of the GPs' accounts suggested a long-standing knowledge of the patient and an individual appraisal of their health impairments after discharge, they lacked detailed medical knowledge about sepsis complications. The outreach education was mainly well accepted and seemed to provide a valid setting to improve knowledge about specific diagnostic and therapeutic concepts GPs can apply in their professional practice.

### Comparison with existing literature

Patients' perceptions of their quality of life after an ICU-stay have been examined in several qualitative studies<sup>43</sup>. A wide range of ongoing health impairments was identified and loss of autonomy was a main aspect<sup>37</sup><sup>39</sup>. The views of the GPs identified here is very close to patients' perspectives. The GPs also reported general weakness and low functioning as a main aspect and a very individual apprehension of complaints and impairment. This congruence may facilitate a patient-centered after-care especially in a primary care setting.

Difficulties in information flow between intensive care units and GPs had been identified before: lack of information about admission or discharge and ongoing needs of patients after an ICU stay and no involvement in treatment decisions were reported by GPs in other studies<sup>49-51</sup>. As valid data on the course of disease and current diagnoses and treatment is essential for follow-up, information during hospital stay and more detailed discharge information for GPs may be essential to enhance quality in after-care.

It has been shown that GPs lack information on sepsis and identification of post-ICU-complications<sup>29 51</sup>. The acquisition of clinical knowledge has been described and explained by forming of "scripts" with repeated exposure to clinical patterns<sup>52</sup>. With no ongoing experience in handling ICU-patients and limited encounters of post-ICU patients, scripts related to the PICS cannot be expected to evolve in GPs in everyday practice. In our

study, the educational intervention led to additional knowledge about specific post-ICU complications. This may meet patient's ongoing need for feedback of their ICU history, as well as the resulting impairments<sup>43</sup>.

GPs appreciate personal discussion with experts as a valuable method of continuing education<sup>53</sup>, and outreach visits as a method to reach GPs have been used before and shown to be accepted well<sup>30</sup>. Knowledge gain has been demonstrated, but transfer to practice seemed to be difficult<sup>30 54</sup>. Patient-related intervention may be especially helpful<sup>30</sup> to facilitate knowledge transfer. In our study, GPs reported transfer to practice of the knowledge they acquired, which may be achieved by the patient-related education and the individual discussion of diagnosis and treatment in the practice.

Lack of continuum of care is a major patient concern after ICU discharge<sup>37, 38</sup>. The Chronic Care Model can be used to inform the ongoing care at the level of an individual practice, but also to organize patient-centered transsectoral and interdisciplinary care<sup>36</sup>. Local organization of a follow-up multiprofessional network and a stepped-care approach could help to ensure continuity of care. This study demonstrates that GPs are familiar with their patients, know about their medical and psychosocial background and consider these aspects when caring for their patients. Therefore, GPs seem to be appropriate ICU aftercare providers. In addition, increased intersectoral information flow could contribute to ensure continuity of care, e.g. quality of discharge letters may be improved by training, checklists, software solutions or positive peer pressure<sup>55, 56</sup>.

#### Limitations

Since 307 GPs were asked to take part in the trial, and 294 agreed, it is likely those who took part in the trial are representative of other GPs in Germany<sup>34</sup>. Being involved in a sepsis aftercare trial informed GPs about the functioning of the RCTs intervention, but may have changed their perception of the post-sepsis patients they care for. They may have been more preoccupied with and focused on that patient than otherwise. It might be those who agreed to be interviewed were more interested than their peers in sepsis as 4 of the 18 GPs approached for interview declined. As only GPs in the urban area of Berlin were interviewed, specific aspects of GPs in rural settings may have been missed.

The interviews were fairly short, which may limit depth of insights. Time constraints are typical of GPs work and were mentioned repeatedly throughout the interview. As GPs are used to work under pressure, they were able to answer questions quickly and to summarise their experiences. Due to the time pressures they were

under, those interviewed were not contacted again to explore whether they agreed with the researchers' analysis of the data. However, themes and subthemes were discussed repeatedly in the research group.

#### Conclusion

GPs are in a good position to offer continuity of care to sepsis survivors. However, they need training and information flow from secondary care for optimal aftercare provision.

GPs have a profound and holistic knowledge of these complex patients and can appreciate individual their impairments and residual symptoms. However, lack of specific knowledge about critical illness complications and lack of information and communication with ICU care providers are barriers to optimal follow-up in primary care settings.

GPs should get the necessary background knowledge and individual information of their patients to provide high-quality aftercare. Taking into account time constraints and preferred education formats, outreach visits in the context of discharge of a post-ICU patient may be a valuable source of information and support.

#### **Declarations**

Declarations of interest: none declared

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Ethics approval: The protocol of the SMOOTH-trial was approved by the institutional review board of the University of Jena, 26 January 2011 (No.3001/111). The protocol of this interview study was approved by the Ethics Committee of the Charité Universitätsmedizin April 2013 (No.EA4/023/13).

<u>Author Statement:</u> SGB, KS and CH had full access to all of the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. Study concept and design: SGB, CH, JG, KS.

Outreach training conduction: KS. Acquisition, analysis of data: SGB. Interpretation of data: SGB, CH, KS, JG, KT. Drafting of the manuscript: SGB, KS, KT. Critical revision of the manuscript for important intellectual content: SGB, CH, KS, JG, KT.

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<u>Data sharing statement:</u> Audio recordings and transcriptions of the analysed interviews are stored at a secure server of Charité University Medicine and can be shared upon reasonable request.

The BMJ's qualitative reporting checklist has been created based on the reporting guidelines of standards for reporting qualitative research (SRQR).

### Table 1A

# Coding framework: Caring for patients after critical illness

Themes	Subthemes
Continuity of care and	Previous health status
good relationship with	
patients	Personality and illness behavior
patients	Social background
	Continuity of care
GP's experiences during	Lack of information
their patient's critical	Emotional impact
illness	
Impact of persisting	General weakness and limited functioning
symptoms	Alteration to pre-sepsis condition
	Specific diagnosis of common complications after intensive care
	Individual complication

	Individual complication					
Table 1B  Coding framework: Impact of the outreach education						
Themes	Subthemes					
Acceptability	Convenience by outreach visit					
	Time strains, competing tasks					
Improvement of	Persisting elevated mortality after discharge					
knowledge	Specific long-term complications (Polyneuropathy, post-traumatic distress)					
	Diagnosis of sepsis					
	Relevant summary for practice					
Transfer into practice	Identifying complications					
	Initiation of specific therapy					
	Diagnosis of sepsis					
	Low relevance as small patient numbers in practice					

Table 2: Self-declared details of interviewed General Practitioners (GPs)

N. ACD	T a a
No. of GPs	14
Age* (yrs)	41-68
Cov	(mean: 55)
Sex	9 (42 00/)
male female	8 (42.9%) 6 (57.2%)
	0 (37.2%)
Practice organization (no. of GPs) joint practices (2-6 GPs)	6 (57.2%)
single practices	
	8 (42.9%)
license to practice since*	1 (7 10/)
10-20 yrs	1 (7.1%)
20-30 yrs	3 (21.4%)
30-40 yrs	6 (57.2%)
>40 yrs	2 (14.3%)
no data	2 (14.3%)
practice opening (no.)*	1 (7 10/)
< 10 yrs	1 (7.1%)
10-20 yrs	5 (35.7%)
20-30 yrs	4 (28.6%)
30-40 yrs	4 (28.6%)
Specialization (no.)	7 (500()
GPs	7 (50%)
General internists#	6 (57.2%)
Practitioner without specialisation	1 (7.1%)
Practice characteristics,	
subspecialisations§ (no.)	7 (50%) 3 (21.4%) 2 (14.3%) 1 (7.1%) 1 (7.1%) 1 (7.1%) 1 (7.1%) 3 (21.4%)
Complementary medicine	7 (50%)
Psychosomatics Psiconary 1997	3 (21.4%)
Pain management	2 (14.3%)
Gastroenterology	1 (7.1%)
Infectiology	1 (7.1%)
Oncology	1 (7.1%)
Diabetology	1 (7.1%)
Home visits (no/week)	2 (21 40/)
<5/wk	3 (21.4%)
5-10/wk	4 (28.6%)
>10 wk	2 (14.3%)
none	2 (14.3%)
no data	3 (21.4%)
Patients > 60 years (estimate no.)	7 (25 70/)
<30%	5 (35.7%)
30-50%	6 (57.2%)
>50%	2 (14.3%)
Academic teaching practice	T = (500()
yes	7 (50%)
no	7 (50%)

<sup>\*</sup>at the time of the interview § multiple mention possible #A considerable proportion of primary care in Germany is provided by general internists.

Table 3: Characteristics of post-sepsis patients cared for by the General Practitioners (n)

Total Male Female Age [years] 45-82 (mean 66) Sepsis focus 3 pulmonal 2 gastrointestinal 3 unknow. 3 renal

#### Table 4: Quotations - Caring for patients after critical illness

# Themes and subthemes

#### **Ouotation**

#### Continuity of care and good relationship with patients

# Previous health status

"Well, he was a spry patient, he bore his age well and he had no relevant preexisting disease (...) and he came mainly for check-ups." GP 9

"Yes, she needed home visits before. She had an insulin-dependent diabetes, COPD, an heavy nicotine abuse she gave up after a hospital admission, we had home oxygen therapy before, there was a problem with alcohol meanwhile, she had skin problems, heart failure, high blood pressure, all that existed before." GP 5

"A young man, I know him since his school times, over time he developed arterial hypertension. It is obviously in the family, as both his parents suffered from it and a chronic gastritis, apart from this no abnormalities." GP 3

"I didn't have much contact to (him) before, because he was comparatively fit for his age. He predominantly had orthopedic problems. He is still active, playing golf and so on and (..) but internal diseases, that were serious, he didn't have that." GP 8

# Personality and illness behavior

"She was actually- or she is actually a very modest... and shy person and for her medical problems she only claimed what she really needed urgently at that moment. A very kind and pleasant patient." GP 12

"...(she is a) tall and robust woman, with a croaky voice...a heavy smoker, always unhappy. Niggling, unsatisfied and complaining, but also a fighter." GP 6

"but she always was...she was a though woman and she never liked taking pills and she eventually said, it is too much, she can't take it and she got used to the symptoms and she would like to take smaller doses (...), she preferred to be without pills." GP 5

"...well, a rather moaning patient, that came with all kinds of ailments and I considered him generally to be healthier than he himself did. " GP7

### Social background

"She had a quite young daughter. Despite being my age, she had a young daughter and I think that's why she needed to be functioning and go back to work and she needed the money, yes." GP 6

,...he himself less, but his wife is quite depressive and that means eventually one has problems in everyday life." GP 8

"I know the whole family (...) I know him only since about ten years but the rest of the family more than 30 years (...). They are all very scientific, that's what I would say. His wife is in a high position in the administration of veterinary surgeons (...), the son is biologist and works in science and the other daughter is a psychologist." GP 10

"...she had a comparatively young daughter, despite being my age, she has a young daughter and I think that's why she was in need to come back to normal and go working and she needed the money." GP 6

#### Continuity of care

"Well, I basically got to know Mr. (...) only as an acute patient after the hospital admission. He looked for a new GP after this adverse fate happened to him." GP 2

#### GP's experiences during their patient's critical illness

Lack of information

"The event of sepsis itself, as I said, wasn't diagnosed by me, in the practice, but happened in hospital after the operation and that's why I sort of got him back here as everything was finished. I just had to sort of accept that (…) in the end, I didn't have much to do with it and that's why I don't know much about it." GP8

"I only saw him again after rehabilitation, I didn't get a discharge letter either. I only got notice of these things as he stood here in front of me." GP 4

**Emotional** impact

"This was a very unlucky course of events (...) surely, everybody asks, 'why is it just me?" GP 3

"I once visited him in hospital and was shocked (…) well, this was a dramatic story." GP 10

#### Impact of persisting symptoms

# General weakness and low functioning

"Well, she was a shadow of her former self." GP 6

"...he is not up and about again. Well, he can't leave the flat, he walks short distances like to the toilet, from bed to toilet, from bed to living room." GP 11

"I have visited him once in the hospital and was shocked. He could only talk slowly, maybe in an orderly way, but he was heavily impaired after this intensive care therapy. And afterwards, it got better, he became clearer from the cerebral point of view and the slowing, that was extreme, went away." GP 10

"...in the beginning, she needed house visits, well, I can only see that her health condition only improved very slowly over a long period of time. That's all I can say about it." GP 12

### Alteration to presepsis condition

"...but, I must say, (he) had some problems with his peripheral nerves before due to his lifestyle, (due to) alcohol (...) There was some damage before and then, with the sepsis, that only came to the point it became clinically apparent and now that is the situation." GP 2

"...just like before, she has from time to time exacerbations of her COPD." GP 12

"...he had depression before and had depression afterwards and I believe his depression was even less, (...) He had a longstanding depression so you can't put these things (sepsis) forward." GP 10

"...basically, he kept all the diseases he had before and everything grew gradually worse." GP 11

### Specific diagnosis of common complications after intensive care

"...he had this critical illness neuropathy with pains and muscle weakness and at the beginning also psychological problems with insomnia." GP 1

"...now (she suffers from) increasing polyneuropathic pain, that needs to be treated with strong pain killers, with opioids." GP 2

"...well, he still has a post traumatic distress syndrome, he is still looking for a psychologist." GP 4

"...he is impaired a bit by the polyneuropathy." GP 9

# Individual complication

"...because she had, she lost her leg with the sepsis and she, she had an amputation and before she could move about and could leave the apartment. But, afterwards, not anymore because she couldn't manage the stairs with one leg." GP5

....and then she was depressive because she had the colostomy." GP 6

# Table 5: Themes, subthemes and quotations: Impact of outreach education. Themes and Quotation subthemes Acceptability Convenience by "I was approached at a time, I had time and as we arranged it, that was ideal (...) it was announced early enough and I got a mail-reminder an I didn't have to move anywhere, outreach visit that could happen here, well, the colleague was really committed (...) I would say that was ideal." GP 2 "...well, that (the outreach education) happened here in the practice ...nice and friendly... adapted to the needs of the doctor... very good, that was comfortable. Didn't burden me much either." GP 6 ,,...well, it was really very interesting, the training, but this is – like today (the Time strains, competing tasks interview) – just one more thing, that delays and I would rather e.g. go for lunch or something else." GP 11 "We have two thousand patients, work has grown so intense, that one has to leave out everything that is not absolutely necessary." GP 12 Impact on knowledge Persisting elevated "The mortality after discharge, (...) that was very impressive, well, because I thought: mortality after sepsis overcome, well, everything is fine and the bird flies on." GP 2 discharge ,,...that statistic, that said, ok, patients that survived this have a much higher mortality (...) these numbers were quite alarming." GP 5 ,,...well, that was mainly new, that one looks at sepsis as a complex illness with long-Specific long-term complications term complications. I did look at is more as a complication, that, when cured, is presumably good and done with." GP 11 (Polyneuropathy, post-traumatic "...the most helpful was, as I said, the connection. Generally with sepsis, that sepsis distress) can cause other diseases (...) it seems, sepsis can cause serious alterations in the peripheral nerves." GP 2 ,...the fact, that polyneuropathy had a connection to sepsis was not known to me at all." GP 12 "...what kind of symptoms, how sepsis manifests itself, because, one doesn't consider Diagnosis of sepsis it so much, isn't it?" GP 6 Relevant summary for "...we all have learnt that during medical studies, but it is not...one doesn't meet a practice sepsis survivor every day. It is not everyday business. And that's why I found it interesting, that you had it explained again." GP 5 "...in continuing education, we don't get the things that are relevant for practice enough, in that way, it was a nice, short update and training, but nothing really new." GP 8 Transfer to practice "...and since then, I turn my attention more to those symptoms, (...) I really pay Identifying

complications

attention to things now, that I didn't consider before. It really helped me." GP 6

"One is sensitized for it. Yes, I now pay more attention, especially regarding polyneuropathy and so on, I watch more closely, I say, ok, be careful, here you must consider that, that is a case you must watch out and ask , if she doesn't tell herself, whether she has symptoms." GP 5

# Initiation of specific therapy

"...now, I would always look first, that I talk with him about what he went through and how it felt in the hospital, what impressions, what experiences, what feelings and that one really goes on to arrange for psychological care more quickly." GP 4

"...and I also did some of that in practice, I mentioned the referral to a psychologist and that became very clear." GP 4

"...from that training I learnt, that it makes sense, to send the patient to physiotherapy. That it is not only about medication, his usual medication and putting it - may be a bit trivial- I would prescribe antidepressants as well." GP 7

#### Diagnosis of sepsis

"...(reporting a case of postoperative sepsis) and I really was more careful and said, this lady has a sepsis. (...) I now have an eye on these symptoms and I refer more quickly." GP 6

Low relevance as small patient numbers in practice

"I don't have any patients after sepsis, that's why I can't change what I am doing." GP 3

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# Reporting checklist for qualitative study.

Based on the SRQR guidelines.

# Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQRreporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

Page

Reporting Item

Number

Title

#1 Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended

#### Abstract

#2 Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions 

#### Introduction

Problem formulation #3 Description and significance of the problem /

phenomenon studied: review of relevant theory and

empirical work; problem statement

Purpose or research #4 Purpose of the study and specific objectives or question question 6

#### Methods

Qualitative approach and #5 Qualitative approach (e.g. ethnography, grounded research paradigm theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions

and limitations implicit in those choices and how those

choices influence study conclusions and transferability.

As appropriate the rationale for several items might be discussed together.

Researcher
characteristics and
reflexivity

#6

#9

Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability

Context

#7 Setting / site and salient contextual factors; rationale

Sampling strategy

#8 How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale

Ethical issues pertaining to human subjects

Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues

Data collection methods

#10 Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of procedures in response to evolving study findings; rationale

Data collection	<u>#11</u>	Description of instruments (e.g. interview guides,	7
instruments and		questionnaires) and devices (e.g. audio recorders)	
technologies		used for data collection; if / how the instruments(s)	
		changed over the course of the study	
Units of study	<u>#12</u>	Number and relevant characteristics of participants,	8
		documents, or events included in the study; level of	
		participation (could be reported in results)	
Data processing	<u>#13</u>	Methods for processing data prior to and during	7
		analysis, including transcription, data entry, data	
		management and security, verification of data integrity,	
		data coding, and anonymisation / deidentification of	
		excerpts	
Data analysis	<u>#14</u>	Process by which inferences, themes, etc. were	7,8
		identified and developed, including the researchers	
		involved in data analysis; usually references a specific	
		paradigm or approach; rationale	
Techniques to enhance	<u>#15</u>	Techniques to enhance trustworthiness and credibility	7,8
trustworthiness		of data analysis (e.g. member checking, audit trail,	
		triangulation); rationale	
Results/findings			

Syntheses and #16 Main findings (e.g. interpretations, inferences, and interpretation themes); might include development of a theory or model, or integration with prior research or theory

Links to empirical data	<u>#17</u>	Evidence (e.g. quotes, field notes, text excerpts,	24-28		
		photographs) to substantiate analytic findings			
Discussion					
Intergration with prior	<u>#18</u>	Short summary of main findings; explanation of how	13,14		
work, implications,		findings and conclusions connect to, support, elaborate			
transferability and		on, or challenge conclusions of earlier scholarship;			
contribution(s) to the field		discussion of scope of application / generalizability;			
		identification of unique contributions(s) to scholarship			
		in a discipline or field			
Limitationa	#10	Trustworthings and limitations of findings	14		
Limitations	<u>#19</u>	Trustworthiness and limitations of findings	14		
Other					
Conflicts of interest	#20	Potential sources of influence of perceived influence on	15		
	<u>1120</u>		10		
		study conduct and conclusions; how these were			
		managed			
Funding	<u>#21</u>	Sources of funding and other support; role of funders in	15		
		data collection, interpretation and reporting			
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