

2021

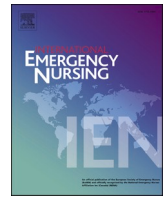
Implementing a person centred collaborative health care model – A qualitative study on patient experiences

Jenny Hallgren

Karin Bergman

Maria Klingberg

Catharina Gillsjö



Implementing a person centred collaborative health care model – A qualitative study on patient experiences

Jenny Hallgren^{a,*}, Karin Bergman^a, Maria Klingberg^b, Catharina Gillsjö^{a,c}

^a School of Health Sciences, University of Skövde, Skövde, Sweden

^b Collaborative Health Care, Uddevalla, Sweden

^c College of Nursing, University of Rhode Island, Kingston, USA

ARTICLE INFO

Keywords:

Collaborative health care model
Qualitative content analysis
Swedish health care direct (SHD1177)
While waiting for ambulance
Assistance-missions

ABSTRACT

Background: Collaborative Health Care (CHC) is a unique model in which ambulance services, home health care, hospital care and the national telephone helpline for healthcare in Sweden – Swedish health care direct (SHD1177) collaborate to provide the fastest possible health care for inhabitants living in eleven municipalities in western region of Sweden.

Aim: To explore how patients experience and perceive health care received in the CHC.

Method: Qualitative descriptive study using open-ended individual telephone interviews with fifteen community dwelling persons with experiences of care through the model CHC were conducted.

Results: Two main categories and six subcategories were identified. The category “Thoughts of time in regard to acute health care” include “CHC leads to shorter waiting time for health care”, “Knowledge about the staff working hours” and “To alert or not alert”. The category “Thoughts on unplanned health care from CHC” involved “Receiving health care in my home”, “Coordination from SHD1177 surprises” and “Accessibility of health care values higher than continuity”.

Conclusion: Integrated health care models such as CHC are time saving and highly appreciated by community dwelling persons. The benefits of provision of coherent health care like in CHC, addresses the need to implement innovative integrated healthcare models in today’s health care.

1. Background

Need of services from health – and social care often increase with age since multiple diseases and health problems are frequent among older persons [1]. It is challenging and demanding to provide health and social care services that meet the needs of this growing number of older persons [2]. Prior European research implies the importance of a robust primary health care system to improve public health [3]. Improved access and increased continuity of primary health care has been shown to be associated with reduced unscheduled care, emergency department attendance, and ambulatory care sensitive conditions (ACSC) [4,5]. However, some persons, especially frail and persons with multiple diseases, have difficulties with transfer to a primary health care center and often call for an ambulance instead [6]. Professionals find it difficult to

prioritize the emergency calls in the dispatch center [7] and sense a struggle between different expectations in the care of patients assessed not being in need of emergency ambulance care [8], results in patients being both over- and under prioritized [7]. Difficulties to prioritize emergency calls may lead to high emergency ambulance services use for provision of care associated with ACSC. This includes not only services related to provision of care in ordinary homes but also to older persons with health problems as dementia in assisted living facilities [9]. In order to meet the challenges with expanding care needs of an aging population, Person-centred care (PCC) is advocated by the World Health Organization as a global strategy, which entails a paradigm shift in the way health services are funded, managed and delivered [10]. The shift to PCC requires a move from profession- and disease- centeredness to focus on individual health care needs and expectations of patients

Abbreviations: ACSC, Ambulatory care sensitive conditions; CHC, Collaborative Health Care; PCC, Person-centred care; SHD1177, Swedish health care direct; WWFA, While Waiting for Ambulance.

* Corresponding author at: School of Health Sciences, University of Skövde, Skövde, Sweden.

E-mail addresses: jenny.hallgren@his.se (J. Hallgren), karin.bergman@his.se (K. Bergman), maria.klingberg@vgregion.se (M. Klingberg), catharina.gillsjo@his.se (C. Gillsjö).

<https://doi.org/10.1016/j.ienj.2021.101068>

Received 8 March 2021; Received in revised form 24 June 2021; Accepted 5 August 2021

Available online 27 September 2021

1755-599X/© 2021 The Author(s). Published by Elsevier Ltd. This is an open access article under the CC BY license (<http://creativecommons.org/licenses/by/4.0/>).

[10,11]. Furthermore, in order to overcome the fragmentations in care delivery, coordination of different health care services is needed. PCC is recognized as a core competency in nursing [3], and evidence has been shown of its effectiveness in various clinical areas [11], as well as in controlled trials [4] as in the care of older persons [12,13].

It is difficult to find successful case management programs in primary health care aiming at reducing the risk of unplanned hospital admissions [14]. A recent systematic review suggests that factors other than the acuteness of the medical emergency, have an impact on the decisions to refer or not refer to the emergency department [15]. However, research on factors related to patients' experiences of health care utilization in primary health care and ambulance care services is scarce [16,17].

2. Aim

The aim of this study was to explore how patients experience and perceive health care received in the Collaborative Health Care model.

3. Methods

3.1. Design

A qualitative, descriptive design was used to explore patients' experiences regarding health care received through the health care model Collaborative Health Care (CHC). Qualitative content analysis was used to analyze the data. This study is reported using the COREQ checklist for reporting qualitative research [18].

3.2. Setting

The health care model CHC, was developed to coordinate health care resources, to tighten the care chain in primary health care, and to provide coherent health care. The CHC model is a unique health care model in Sweden, in which ambulance services including SOS alarm, hospital care, home health care and the national telephone helpline for health-care in Sweden – Swedish healthcare direct (SHD1177), collaborate. The model is developed in order to provide the most adequate and fastest possible health care for inhabitants living in one of the eleven municipalities working according to the CHC model in the western region of Sweden. Normally in Sweden, each health care unit (ambulance services, home health care, hospital care and SHD1177) work independently due to separated authorities and organizations. Accountable managers for each actor in the region, have in collaboration developed the CHC model, to develop a coherent and seamless health care in which the health care actors share responsibilities in provision of care, organization, and financing. The CHC model has been perceived to increase person-centredness and quality in the health care, by the professionals working in the care model [18]. However, there is a lack of research regarding patients' experiences of CHC.

Participants with experiences of care in the model CHC were recruited from three of eleven feasible municipalities. Inclusion criteria were, experience from one of the following health and medical care actions;

SHD1177-function, where a RN answers phone calls at SHD1177, and then coordinate another RN in the home health care to make a home visit if needed.

While Waiting for Ambulance (WWFA) is a function or service when an operator at the SOS-alarm system coordinate the closest RN in the home health care to start up all actions needed to support the person calling SOS, while waiting for the ambulance to arrive.

Assistance-missions are situations when one RN in a health care organization ask for help with nursing interventions from a RN in another health care organization e.g. blood sampling, home visits, ECG.

3.3. Participants

Health care teams delivering one of the listed services provided contact details of persons that had received care and assessed as able to manage an interview (n = 23), to the first and third author (JH, MK), who mailed information letters about the aim of the study. After a week or two, the first author contacted the prospective participants by phone and asked if they were interested to participate in the study. The interviews were to be carried out in person or via telephone, based on the participant's request. An appointment for interview was set with those who consented to participate based on their wishes regarding place, date and time. Of the twenty-three contacted persons, fifteen agreed to participate in the study, all preferred telephone interviews. Not willing or able to perform an interview were reasons stated among the eight persons who refused to participate. Oral informed consent was obtained at two occasions, once in the telephone call, and secondly when the interview took place.

Data was collected with open-ended individual telephone interviews by the first author (JH) from autumn 2017 to autumn 2018. The interviewer was a RN with several years working within hospital and municipal health care. The interviews lasted between 15 and 45 min (mean 25 min) and were recorded and transcribed verbatim. The interviews were introduced with an overall question, "Could you tell me about your experience of the help you received from Collaborative Health Care?" Probing questions were used depending on the participant's experiences and responses to deepen the content in the interviews.

3.4. Ethical considerations

All participants were informed orally and in written about the content and aim of the study, that their participation was voluntary and could be withdrawn at any time without any negative consequences. The study was approved by the Regional Research Ethics Board in Linköping, Sweden.

3.5. Data analysis

An inductive qualitative content analysis was conducted in accordance with Elo and Kyngäs [19] through the three main phases of preparation, organizing and reporting. In the preparation phase, each interview was read through several times to understand the essential meanings in the text. In the next step, text that responded to the aim of the study was marked and divided into meaning units. The meaning units were further condensed and labelled with codes. The codes were analyzed by comparing differences and similarities and merged into subcategories and categories, describing the manifest content. This process was characterized by iterative movements that continued until agreement emerged among all authors, in order to strengthen credibility. The intention was to form categories that reflected the study aim and covered the data [19]. Quotations are used to illustrate the original data and enhance the description of the categories.

4. Results

Nine participants were women, six were men and age ranged from 60 to 90 (mean 78.3). Twelve participants lived alone, three were cohabiting. Six of the participants had experienced WWFA, six SHD1177-function and three had Assistance-missions (Table 1).

The findings consist of two categories that are further divided into six subcategories. Representative quotes were selected to illustrate the participant's experiences in each subcategory (Table 2).

4.1. Thoughts of time in regard to acute health care

The category *Thoughts of time* involved aspects of time in regard to

Table 1
Characteristics of the study participants.

| Characteristics | Total N = 15 | Men n = 6 | Women n = 9 |
|-----------------------------|--------------|-----------|-------------|
| Age (mean) | 78.3 | 76.2 | 70.8 |
| Living alone, yes | 12 | 5 | 7 |
| SHD1177-function, | 6 | 3 | 3 |
| While Waiting for Ambulance | 6 | 3 | 3 |
| Assistance-missions | 3 | 0 | 3 |

Table 2
The including categories and subcategories.

| Subcategory | Category |
|---|---|
| Collaborative Health Care leads to shorter waiting time for health care | Thoughts of time in regard to acute health care |
| Knowledge about the staffs working hours To alert or not alert | |
| Receiving health care in my home | Thoughts on unplanned health care from CHC |
| Coordination from SHD1177 surprises | |
| Accessibility of health care values higher than continuity | |

health care. Time seemed to be an important issue in regard to when or where to seek acute health care and for what type of health problems. Thoughts of time included "Collaborative Health Care leads to shorter waiting time", "Knowledge about the staff working hours" and "To alert or not alert".

4.1.1. Collaborative health care leads to shorter waiting time for health care

Waiting was experienced to be tough when the need of acute health care increased. Stories were told about how long you usually have to wait for the ambulance to come after being alerted. Having to wait for acute health care were experienced as a normal procedure i.e. alerting ambulance, calling the SHD1177 or visiting emergency department.

"Now it only took 8 min in waiting time,... but another time we had to wait almost an hour... you think twice before calling 1177 I have to say..."

The CHC model was experienced to decrease the waiting time. For instance, when the ambulance was alerted and WWFA was coming quickly, it sometimes arrived several minutes before the ambulance.

"It's very positive since it can take time for the ambulance to come here... it takes at least 20 min or even more... It depends on how much they have to do, so my opinion is that the acute care is very important in this area."

The participants suggested that general health care should be organized as CHC, to ease the burden of thinking about time in regard to provision of healthcare.

4.1.2. Knowledge about the staffs working hours

Participants talked about the home help and home health care staffs working hours and knew when they were in the area and could help. Knowledge about working hours of the staff particularly involved Assistance-missions. Participants that had regular help from the municipality had particularly detailed knowledge about the working hours for the staff, when they ended their shifts in week evenings, nights, and weekends.

"We were fortunate that the nurse hadn't ended her shift since she only works until 9.30 pm, and the clock now was only half past eight."

Participants that did not receive social services or home health care from the municipality, were also updated about the working hours of the staff, based on knowledge received by reading or listening to media or information from family and friends.

4.1.3. To alert or not alert

To alert or not to alert the ambulance was something worth thinking twice about. Alerting the emergency number 112 was perceived as a major event that the participants did not want to do without having

thought it through properly with no other solution in sight. One did not want the ambulance to come in vain. The participants knew that there is a lack of ambulances. They explained that if you alert the ambulance in vain, someone else might need it better, and will have to wait for a longer time than needed.

One participant said "One has learned to not alert an ambulance if it is not necessary. You do not make a fuzz if it is not needed. One has to wait and see...the situation might improve".

The participants described how they did not want to bother the SOS-alarm, almost as it was associated with shame to alert.

"One does not need to send fully equipped ambulances and personnel to patients in situations that do not need to be dealt with acute".

The importance of using the society's resources in the most proper way was conveyed. Another participant sent away the ambulance when they wanted to take her to the hospital, since she already had got the help needed from WWFA.

4.2. Thoughts on unplanned health care from CHC

The category "Thoughts on unplanned health care from CHC" involved "Receiving health care in my home", "Coordination from SHD1177 surprises" and "Accessibility of health care values higher than continuity". Thoughts were expressed in regard to how different practical issues were experienced when receiving acute health care compared to their preunderstandings of the health care that they had expected to receive.

4.2.1. Receiving health care in my home

To receive help in one's own home was described as a positive experience. Not being forced to travel to neither the primary health care center nor to the hospital was experienced as astonishing. Most participants had a preconception about what type of care they could receive at home. Most of them knew that you would normally not receive health care if you are not enrolled in home health care. One participant described that having health care in one's own house was experienced and conveyed as a sense of being "back in the old days when you had a family physician". The person referred to the time when all citizens had their own physician that conducted home visits.

"Yes it's fantastic that you can receive help at home from a nurse without being forced to leave home or call for an ambulance, especially when it is not necessary."

4.2.2. Coordination from SHD1177 surprises

Many participants knew and most of them had called the SHD1177 at some point for advice regarding acute health care matters. The ability for health care personnel at the SHD1177 to work as coordinators and send out home health care nurses came as a surprise for the majority of the participants. Most of the participants knew about the service of receiving advice and guidance through SHD1177 when being in need of talking to a professional health care personnel. But none of them knew that personnel at SHD1177 also could offer a physical meeting with a home health care nurse when needed. One participant described calling the SHD1177 when having chest pain. Based on the symptoms, the SHD1177 personnel took the decision to send an ambulance. According to the participant, it felt good and safe to not have to make the decision about alerting the ambulance oneself. Another participant described being surprised when achieving an unexpected visit from a registered nurse after calling the SHD1177.

"We got totally surprised when that happened...we thought that something was wrong and thought that this is not happening to us"

Coordination of provision of health care through the 1177 was really an unexpected, although positive experience that surprised the participants.

4.2.3. Accessibility of health care values higher than continuity

The participants talked about how important it is to have health care

that is highly accessible. Having resources as CHC is fantastic, however, many had noticed the trend in the diverse direction with hospitals closing down and one is referred to larger, centralized hospitals. Several participants had also experienced lack of continuity in meeting with different physicians in primary health care and in the provision of home health care carried out by different registered nurses which was perceived as negative. They requested continuity in the ongoing provision of health care. Experiences from CHC on the other hand were perceived differently. Continuity was experienced as being less important when it comes to acute situations. The most important thing being considered was that the health care staff have the skills to perform the duties expected. The participants preferred to receive help from a health care provider even one they were not familiar with, instead of having to wait for a person they were familiar with.

“...in regard to provision of social services I had preferred to be cared for by persons I know, however, that is totally irrelevant when it comes to need of acute care from health care providers working in ambulances.”

One participant that had received several visits at home by calling SHD1177 had met different registered nurses every time and did not have any problem with that. Continuity was perceived as less important when one needed acute health care.

5. Discussion

Health care authorities usually focus on their primary responsibility regarding provision of health care and more seldom on collaboration in providing coherent and holistic health care from the patients point of view [17]. This can be viewed in light of the findings in this study since the patients were surprised of how the new integrated care model, CHC, met their healthcare needs in regard to time, efficiency and received health care through the collaboration across organizations and professions. The findings in this study highlights the significance of healthcare models focusing on addressing the patients perspective and needs on collaboration and integration of care rather than on what is most convenient or efficient within each organization, which is addressed in previous research [20]. The findings supports the fundamentals argued for use of a person-centred care approach; the need to move from organization-, profession- and disease oriented health care delivery towards focusing on each individuals experience, health care needs and expectations [10,11]. Time was central in the findings, every minute that the waiting process can be shortened was valuable, which is supported in prior research [21]. Sometimes time saving working models are preferred compared to continuity for efficiency which the findings in this study support in regard to acute situations. This contrast previous research showing that continuity is of major importance for patients receiving primary care and home health care [6,22]. However, the participants in this study emphasized that the priority when receiving acute health care is different from situations with planned health care. This highlight the need of health care models such as CHC with collaboration across health care authorities, in provision of health care outside the hospital in acute or semi acute situations.

Prior European research have suggested an improved information infrastructure to facilitate primary health care performance management [3]. The findings show that several participants had knowledge about the health care organization in their region including the working hours for the staff. However, parts of the new health care model in CHC surprised, especially those that did not follow the normal procedure such as the extension in responsibilities for SHD1177 and collaboration in services between SHD1177, home health care and the ambulance. It is obvious that the participants found it unexpected but positive to be able to receive acute health care in ones own home without having regular services from home health care. Receiving consistent information that is effective and timely communicated about health care, has been found to be of importance for patients [21]. Consistent information on when and how to alert the health care in acute situations is of importance. The findings in the study also reveal that the participants did not want to

utilize the emergency number unless it was absolute necessary because of a fear of alerting an ambulance that someone else might need better. This support prior research revealing how patients perceive a strong need of being taken seriously when being triaged as non-emergency, when having called for an ambulance [17]. It has been found that patients define need of emergency ambulance according to both physical symptoms, but also complex socioemotional factors, and it can be a mismatch on how patients and professionals define emergency situations [23]. It is likely that patients are well aware of the potential in the primary health care section and make a thoughtful decision to alert an ambulance instead. For instance, Amador et al. (2014) indicate that patients that frequently call on GPs are more likely to call for emergency ambulance services.

6. Strengths and limitations

The strength in this study is the exploring of the novel and unique health care model from the patients perspective. To our knowledge no prior research exist focusing on the patients' perspective in receiving health care based on the model CHC. There are however some limitations in this study. The interviews were carried out by telephone to meet the requests of the participants. Interviews made face to face might have rendered a deeper conversation and reflection. The participants were informed that the first author carrying out the interviews, were not employed or connected to CHC in order to facilitate both positive and negative experiences of the model. Every participant in this study also expressed that they were able to talk freely about their experiences and offered to be available for further questions if needed. Although the age ranged from 60 to 90 years, the mean age was high among the included participants, and many were living alone, that might have had an impact on the results. Further studies including younger persons, as well as other aspects of the CHC as the model evolves, are warranted.

7. Conclusions and implications

To conclude, the findings suggest that integrated health care models such as CHC and other health care models offering home visits are time saving and highly appreciated by community dwelling persons. To meet patients needs and expectations, it is essential to increase development and implementation of innovative integrated health care models as CHS to provide a person-centred, coherent, efficient and holistic health care across borders. Whether the actions and provision of health care carried out by health care authorities in this study have prevented hospitalization is not investigated in this paper. However, it is not unlikely that the health care model CHC results in fewer visits to primary health care centers and emergency departments. The health care model is also a way to carry out person-centred care which is an approach that is expected to be a part of today's provision of health care. Further research on organizational perspective as well as research on health care professionals' perception are warranted in regard to the CHC model.

Availability of data and materials

Data underlying this article cannot be shared publicly due to ethical issues.

Ethical statement and consent to participate

This study was conducted in accordance with the Declaration of Helsinki. The data collection and storage were approved by the Regional Research Ethics Board in Linköping, Sweden. All participants were informed orally and in written about the content and aim of the study. Oral consent was obtained from the participants for their information to be published as a research article.

Funding

The project did not receive any external funding.

CRedit authorship contribution statement

Jenny Hallgren: Project administration, Conceptualization, Methodology, Writing - original draft, Writing - review & editing. **Karin Bergman:** Writing - review & editing. **Maria Klingberg:** Project administration, Conceptualization, Writing - review & editing. **Catharina Gillsjö:** Writing - review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

Acknowledgements

We wish to acknowledge the participants in this study as well as the health care professionals involved in the Collaborative Health Care model.

References

- [1] Ernsth-Bravell M, Mölstad S. Easy-to-use definition of frailty for guiding care decisions in elderly individuals: probability or utopia? *Aging Health*. 2010;6(6): 697–9.
- [2] Sou SOU. *Effektiv vård*. Stockholm 2016.
- [3] Kringos DS, Boerma W, van der Zee J, Groenewegen P. Europe's strong primary care systems are linked to better population health but also to higher health spending. *Health Aff* 2013;32(4):686–94.
- [4] Huntley A, Lasserson D, Wye L, Morris R, Checkland K, England H, et al. Which features of primary care affect unscheduled secondary care use? a systematic review. *BMJ open*. 2014;4(5):e004746. <https://doi.org/10.1136/bmjopen-2013-004746>.
- [5] Barker I, Steventon A, Deeny SR. Association between continuity of care in general practice and hospital admissions for ambulatory care sensitive conditions: cross sectional study of routinely collected, person level data. *BMJ* 2017;356:j84.
- [6] Hallgren J, Ernsth Bravell M, Dahl Aslan AK, Josephson I. In Hospital We Trust: Experiences of older peoples' decision to seek hospital care. *Geriatr Nurs* 2015;36(4):306–11.
- [7] Ek B, Edström P, Toutin A, Svedlund M. Reliability of a Swedish pre-hospital dispatch system in prioritizing patients. *Int Emerg Nurs* 2013;21(2):143–9.
- [8] Barrientos C, Holmberg M. The care of patients assessed as not in need of emergency ambulance care – registered nurses' lived experiences. *Int Emerg Nurs* 2018;38:10–4.
- [9] Amador S, Goodman C, King D, Machen I, Elmore N, Mathie E, et al. Emergency ambulance service involvement with residential care homes in the support of older people with dementia: an observational study. *BMC Geriatr* 2014;14(1). <https://doi.org/10.1186/1471-2318-14-95>.
- [10] Organization WH. WHO global strategy on people-centred and integrated health services: interim report. World Health Organization; 2015.
- [11] Phelan A, McCormack B, Dewing J, Brown D, Cardiff S, Cook NF, et al. Review of developments in person-centred healthcare. *Int Practice Develop J* 2020.
- [12] McCormack B, Dewing J, Mccance T. Developing person-centred care: addressing contextual challenges through practice development, 2011.
- [13] Edvardsson D, Winblad B, Sandman PO. Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *Lancet Neurol* 2008;7(4): 362–7.
- [14] Huntley AL, Thomas R, Mann M, Huws D, Elwyn G, Paranjothy S, et al. Is case management effective in reducing the risk of unplanned hospital admissions for older people? a systematic review and meta-analysis. *Fam Pract* 2013;30(3): 266–75.
- [15] Oosterwold J, Sagel D, Berben S, Roodbol P, Broekhuis M. Factors influencing the decision to convey or not to convey elderly people to the emergency department after emergency ambulance attendance: a systematic mixed studies review. *BMJ open*. 2018;8(8):e021732. <https://doi.org/10.1136/bmjopen-2018-021732.1136/bmjopen-2018-021732.supp110.1136/bmjopen-2018-021732.supp2>.
- [16] Spiers G, Matthews FE, Moffatt S, Barker R, Jarvis H, Stow D, et al. Does older adults' use of social care influence their healthcare utilisation? a systematic review of international evidence. *Health Soc Care Community* 2019;27(5):e651–62.
- [17] Rantala A, Ekwall A, Forsberg A. The meaning of being triaged to non-emergency ambulance care as experienced by patients. *Int Emerg Nurs* 2016;25:65–70.
- [18] Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care* 2007;19(6):349–57.
- [19] Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs* 2008;62(1): 107–15.
- [20] Luxford K, Safran DG, Delbanco T, Luxford K, Safran DG, Delbanco T. Promoting patient-centered care: a qualitative study of facilitators and barriers in healthcare organizations with a reputation for improving the patient experience. *Int J Qual Health Care* 2011;23(5):510–5.
- [21] Mattarozzi K, Sfrisi F, Caniglia F, De Palma A, Martoni M. What patients' complaints and praise tell the health practitioner: implications for health care quality. A qualitative research study. *Int J Qual Health Care* 2017;29(1):83–9.
- [22] Greenfield G, Ignatowicz AM, Belsi A, Pappas Y, Car J, Majeed A, et al. Wake up, wake up! It's me! It's my life! patient narratives on person-centeredness in the integrated care context: a qualitative study. *BMC Health Serv Res* 2014;14(1). <https://doi.org/10.1186/s12913-014-0619-9>.
- [23] Booker MJ, Purdy S, Shaw ARG. Seeking ambulance treatment for 'primary care' problems: a qualitative systematic review of patient, carer and professional perspectives. *BMJ open*. 2017;7(8):e016832. <https://doi.org/10.1136/bmjopen-2017-016832.1136/bmjopen-2017-016832.supp1>.