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#### Interrelation between illness representation and selfreported degree-of-worry in patients calling out-of-hours services: a mixed methods study

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|                                      |  |



## Interrelation between illness representation and self-reported degree-of-worry in patients calling out-of-hours services: a mixed methods study

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#### ABSTRACT

#### **Objectives:**

To examine the interrelation between patients' illness representations, presented in telephone consultation to out-of-hours (OOH) services, and self-reported degree-of-worry (DOW), as a measure of self-evaluated urgency. If a clear interrelation is found, incorporating DOW during telephone triage could aid the triage process, potentially increasing patient safety.

#### Design:

A convergent parallel mixed methods design with quantitative data; DOW and qualitative data; recorded telephone consultations. Thematic analysis of the qualitative data was used to explore the content of the quantitative scaled DOW, using the Common Sense Model of Self-Regulation (CSM).

#### Setting:

A convenience sampling of calls to the OOH services in Copenhagen, the Capital Region of Denmark, during three days was included in the study.

#### Participants:

All calls from adults (≥15 years of age) concerning somatic illness during the data collection period were eligible for inclusion. Calls made on behalf of another person, calls concerning perceived life-threatening illness or calls regarding non-healthcare related logistical/practical problems were excluded, resulting in analysis of 180 calls.

#### **Results:**

All five components of the CSM framework, regardless of DOW, were present in the data. All callers referred to identity and timeline and were least likely to refer to consequence. Callers with a strong identity, illness duration of less than 5 hours, clear cause and solution for cure/control were more likely to present a low DOW. Callers with a medium identity, illness duration of more than 24 hours and a high consequence were more likely to present a high DOW.

#### **Conclusion:**

This study suggests an interrelation between a patient's illness representation and self-evaluation of urgency. Incorporating a patient's DOW during telephone triage could aid the triage process in determining urgency and type of health care needed, potentially increasing patient safety. Research on patient outcome after DOW-assisted triage is needed before implementation of the DOW scale is recommended.

#### Article summary:

#### Strengths and limitations of this study

- This study gives a detailed insight into patients' illness representation in an OOH service, which can enable a better understanding of the challenges described in telephone consultations.
- The use of mixed methods enables a thorough analysis and understanding of the illness representation of patients to an OOH service.
- Patients' presentation of their illness representation and reported self-evaluation of their DOW were obtained at the actual time of seeking help and therefore, not influenced by recall bias.
- All coding of the transcribed calls was performed by the researcher, whereby study results could be subjected to personal bias.
- Use of the NVivo V.11 software and researcher triangulation ensures that the coding of the data is available for independent analysis and less subject to personal bias.

#### INTRODUCTION

Telephone triage within out-of-hours (OOH) service is recognized as a mean to reduce pressure and overcrowding of emergency departments and OOH clinics.<sup>1</sup> It aims to assess the urgency of a patient's medical condition in order to determine the correct type of health care needed, thus ensuring patient safety. However, due to the lack of non-verbal cues in telephone consultations, assessing urgency is more challenging than face-to-face consultations.<sup>2</sup> Studies show that the quality of telephone triage improves with communication between patient and health professional being patient-centred rather than disease-centred<sup>3</sup> and that non-normative symptom and poor communication description contribute to under-triage.<sup>4</sup> Triage tools, e.g. computerized decision support systems are used to aid the triage process<sup>5</sup>; however these tools focus on medical information and less on psychosocial or affective information.<sup>6</sup> Incorporating the patient's selfevaluation of urgency, defined as degree-of-worry (DOW), with the use of a verbal ten-point numerical rating scale (1=minimal worry to 10=maximal worry) could therefore be a useful additional tool in the triage processs.

The Common-Sense Model of Self-Regulation (CSM), by Leventhal<sup>7</sup> is a widely recognized theoretical framework, which can be used to describe how a patient cognitively and emotionally addresses a health threat, based on experienced symptoms. The patient's perception is based on prior experience, personal beliefs, discussions with others and cultural understandings.<sup>8</sup> The CSM is a parallel processing model, with one arm representing the cognitive processing aspects and the other arm representing the emotional processing aspects. Together they make up a patients' illness representation.<sup>9</sup> The cognitive arm can be categorized into five components: 1) *identity*: symptoms or name/label of the health threat, 2) *timeline*: duration of the health threat 3) *cause*: factors that are responsible for the health threat, 4) *cure or control*: whether the health threat can be cured or controlled and 5) *consequence*: of the health threat.<sup>8</sup> The patient's understanding of her illness representation influences how she presents her health issue to a health care provider and this may in turn influence the care she receives.<sup>10</sup> In previous studies, it has been shown that the five components of the CSM framework account for a large proportion of the presentations patients make when contacting OOH services<sup>11</sup> and serve as an appropriate framework for understanding the worry experiences of primary health care patients.<sup>12</sup>

The aim of this paper is to examine the interrelation between a patient's illness representation, as presented in telephone consultation to an OOH service call handler, and the self-reported DOW as a measure of self-evaluated urgency. If there is an interrelation, incorporating a patient's DOW as an additional tool in the telephone triage process could aid determination of urgency and type of health care needed, potentially increasing patient safety.

#### METHOD

#### Design

A convergent parallel mixed methods design with simultaneously collected data was used. This design allows for the transformation of one type of result to another (e.g. themes into counts).<sup>13</sup> Quantitative data consisted of DOW and qualitative data of recorded telephone consultations.

Deductive thematic analysis of the qualitative data was conducted and used to explore the content of the quantitatively scaled DOW, using the framework of the CSM theory.

#### Setting

The OOH services and the Emergency Medical Services, Copenhagen, the Capital Region of Denmark, are integrated in one organization and can be reached through two telephone numbers; 112 for life-threatening emergencies and 1813 for acute, non-emergent medical calls. The Medical Helpline 1813 is available from 4pm to 8am on weekdays and around the clock on weekends and holidays. Citizens may also call 1813 for a referral to an emergency department, if they cannot get in touch with their GP during regular working hours. All access to acute care is pre-assessed by telephone triage. Annually, approximately one million calls are handled by call handlers (nurses/physicians) who triage the caller to self-care, a general practitioner, face-to-face assessment/consultation at a hospital, home visit or direct hospitalisation.<sup>14 15</sup>

#### Data collection

A convenience sample of 180 calls to the OOH services during a three-day time period was included. All calls from adults (≥15 years of age) concerning somatic illness were deemed eligible for inclusion. Calls made on behalf of another person, calls concerning life-threatening problems and calls regarding non-health care related logistical/practical problems (e.g. questions about transportation to clinic) or clarifying questions were excluded. Data were collected for three consecutive days: Wednesday 20<sup>th</sup> April and Thursday 21<sup>st</sup> April (4pm to 10pm) and Friday 22<sup>nd</sup> April (8am to 4pm) 2016 (a bank holiday), 2016.

#### Data sources

Data consisted of two parallel strands – the quantitative scaled DOW and illness representation presented by the callers – both derived from the recorded telephone consultations. Prior to data collection, two experienced call handlers were asked to assess and recommend revisions in question sequence and phrasing in actual calls. All call handlers were invited to participate in data collection and received instructions on procedure, inclusion criteria, study focus and voluntary caller participation. Data collection was obtained during the general telephone consultation by the call handler posing the following question: "How worried would you say you are on a scale from 1 to 10, about the condition you are calling about today?" If the caller failed to provide a number reflecting her DOW, an intensity descriptor<sup>16</sup> was used to give a numeric value (1 to 10). These calls were assessed by two researchers and if not concurrent, a consensus was reached through discussion.

#### ANALYSIS

The recorded telephone consultations were transcribed in NVivo V.11 and DOW were attached to each call as attributes. Symptom duration was categorized into three groups: less than 5 hours, 5 to 24 hours and more than 24 hours. The remaining qualitative data were deductively coded according to the last four components of the CSM framework. For the purpose of simplicity, the results were then sub-grouped into: low DOW (DOW 1 to 4), moderate DOW (DOW 5 and 6) and

high DOW (DOW 7 to 10). Furthermore the results were compared to two previous studies: Farquharson *et al*<sup>10</sup> and Lau *et al*.<sup>17</sup>

#### Qualitative data analysis

The qualitative data were created by coding the transcripts deductively according to the five components of the CSM framework, while blinded for the DOW value. For each component, data were clustered into themes and recoded, as described by Braun and Clarke.<sup>18</sup>

#### Mixed methods analysis

All 180 calls were grouped according to themes in each of the five CSM components and listed according to DOW (1-10). For each theme, the quantiles (Q1-Q3) and median were calculated and a box and whisker plot created.

#### RESULTS

#### Participants

A total of 261 callers to the OOH services during the three-day time period were approached for inclusion. Of these, 81 callers were excluded, based on the exclusion criteria, leaving a total of 180 callers to be included in this study (figure 1).

#### Quantitative findings according to the CSM framework

All callers referred to identity, as well as duration (timeline) of their symptoms (table 1). Callers with a low DOW were more likely to mention a cause for their illness than other callers, whereas, reference to cure/control was similar in all three DOW sub-groups. Callers in all three DOW subgroups were least likely to refer to consequence compared to the other four CSM components; however, callers with a high DOW were more likely to refer to a consequence of their illness than callers with moderate or low DOW (figure 2).

#### **Qualitative findings**

#### Identity

Callers' referrals to the identity of their perceived health threat were divided into three themes: Strong identity; use of a definitive label or diagnosis, reference to a previous identical experience, reference to a known condition and/or expression of certainty (n=56), *medium identity*; hypothesis of label or diagnosis, reference to a previous similar, but not identical experience and/or expression of near certainty (n=90) and *weak identity*; no mention of label or diagnosis, no reference to a previous experience, reference to an unknown condition and/or expression of uncertainty (n=34).

#### Timeline

Fifty-two callers described symptoms which had lasted *less than 5 hours*, 44 callers described symptoms which had lasted *between 5 and 24 hours* and 84 callers described symptoms which had lasted *more than 24 hours*.

#### Cause

A possible cause of symptoms or illness was reported by 132 callers (73%). The reported causes were divided into the following three themes: *clear cause*; expression of certainty (n=90); *unclear cause*; a hypothesis suggested or expression of uncertainty (n=42); and *no mention of cause* (n=48).

#### Cure/control

Reference pertaining to a cure or control related to their symptoms or illness was made by 138 callers (77%). These were divided in to the following three themes: *clear solution for cure/control*; specific request for treatment (n=42), *unclear solution for cure/control*; suggestion for treatment or had attempted self-treatment with little or no effect (n=96), and *no mention of cure/control* (n=42).

#### Consequence

Reference to a consequence of their symptoms or illness was made by 67 callers (37%). These were categorized into the following three themes: *high consequence*; potentially long-term or life-threatening consequences and consequences severely affecting work or social life (n=36), *low consequence;* short-term consequences, consequences affecting immediate daily life or mildly affecting work or social life (n=31) and *no mention of consequence* (n=113).

#### **Mixed methods findings**

Study callers with a *medium identity* were more likely to have the highest DOWs, while callers with a *strong identity* generally had a lower DOW and callers with a *weak identity* generally had more moderate DOWs. Callers whose illness had lasted *less than 5 hours* were more likely to have a low to moderate DOW, whereas callers whose illness had lasted *more than 24 hours* were more likely to have a more moderate to high DOW. Callers with a *clear cause* for their illness and a *clear solution for cure/control* were more likely to have a low DOW and finally, callers who mentioned a *high consequence* to their illness were more likely to have a high DOW. (See figure 3 for box and whisker plot describing the interrelation between DOW and the five components of the CSM.)

#### DISCUSSION

#### Summary of main findings

Using the five components of the CSM framework, as described by Leventhal,<sup>8</sup> our analysis demonstrated that callers presenting their illness to OOH services to a large extent referred to all

five components, regardless of their self-evaluated DOW. All callers referred to identity and timeline and callers were least likely to refer to consequence.

A low DOW was more present within the group of callers who had a strong illness identity, illness duration of less than five hours, a clear cause and a clear solution. Callers who presented a medium or weak illness identity, illness duration of more than 24 hours and, an unclear cause and unclear solution and a perception of high consequence were more likely to present a higher DOW.

#### Strengths and limitations of this study

The main strength of the methodology used in this study was the number of patients included and that the patient's illness representation and reported self-evaluation of her DOW were obtained in real time, as the caller was seeking help. Therefore, the findings were not influenced by recall bias. A limitation of this study was that all coding of the transcribed calls according to the five components of the CSM and their themes was performed by the primary researcher (SLB), whereby results may be subjected to personal bias. However, use of the NVivo V.11 software and researcher triangulation ensure that the coding of the data is available for independent analysis and less subject to personal bias.

#### Comparison with existing literature

The results of the quantitative data can be compared to work done by Farquharson *et al*<sup>10</sup> and Lau *et al*<sup>19</sup> (table 1). Participants in both studies and in all three DOW sub-groups in the present study mentioned factors pertaining to all five components of the CSM framework. Farquharson *et al*, however, solely based their data on information that callers volunteered, without call handler prompting, but suggested that it may be necessary for call handlers to prompt remaining components to obtain a comprehensive understanding of patients' representations of illness.<sup>20</sup> In this study, all information from the caller was coded, including information prompted by the call handler, thus the prevalence in each of the five CSM components was greater compared to those found by Farquharson et al. The method used in this study provides a more complete portrayal of the caller's illness representation and is more representative of a real-life call to OOH services.

#### Relevance of this study: possible implications for health care providers and policy makers

This study suggests that there is an interrelation between a patient's illness representation, as presented telephonically to an OOH services call handler, and the self-evaluation of urgency, defined as DOW. Incorporating a patient's self-reported DOW as an additional tool in the telephone triage process could therefore increase patient participation and aid in the determination of urgency and the type of health care needed, thus increasing patient safety. Research on optimal patient outcome after DOW-assisted triage is needed before implementation of the DOW scale is recommended.

#### <u>Tables</u>

|              | Present study      |                         |                     | Previous studies                                     |   |
|--------------|--------------------|-------------------------|---------------------|--|---|
|              | Low<br>DOW<br>N=76 | Moderate<br>DOW<br>N=39 | High<br>DOW<br>N=65 | Farquharson et al. <sup>(10)</sup><br>(2011)<br>N=59 | Lau et al. <sup>(16)</sup><br>(1989)<br>N=887 |
| Identity     | 100                | 100                     | 100                 | 100  | 96  |
| Timeline     | 100                | 100                     | 100                 | 44   | 49  |
| Cause        | 82                 | 72                      | 65                  | 15   | 28  |
| Cure/control | 78                 | 79                      | 74                  | 37   | 32  |
| Consequence  | 33                 | 28                      | 48                  | 14   | 33  |
|              |                    | •                       |                     |  | •   |

Table 1. Prevalence (%) of components of illness representation

| <b>Identity</b><br>n=180<br>(100%) | Themes                               | Examples of citations  |
|------------------------------------|--------------------------------------|--|
|                                    | Strong identity<br>n=56 (31%)        | "I have a bladder infectionI have to pee all the<br>timeI also had a UTI last summer"<br>"I rubbed my eye and now it is red and there is<br>pus it is an eye infectionI know it goes away,<br>as I have had it before" |
|                                    | <b>Medium identity</b><br>n=90 (50%) | "I have had genital herpes many times before,<br>but it looks differentmaybe it is just a yeast<br>infection"<br>"sudden pain after I sneezedI think I might<br>have punctured a lung or bruised a rib"                |
|                                    | Weak identity<br>n=34 (19%)          | "I suddenly got a severe pain in the left, lower<br>side of my abdomenI have never tried anything<br>like it beforeI cannot figure out why I am in so<br>much pain"  |
|                                    |                                      | "I have had two attacks of chest pain and cold<br>sweatsI do not usually feel like thisdoes not<br>feel like pain that I have tried beforeI just want<br>to know why"  |
| Timeline<br>n=180                  | < <b>5 hours</b><br>n=52 (29%)       |  |
| (100%)                             | <b>5-24 hours</b><br>n=44 (24%)      |  |
|                                    | >24 hours                            |  |

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|                                | n=84 (47%)   |   |
|--------------------------------|--|---|
| Cause<br>n=132                 | Themes   | Examples of citations   |
| (73%)                          |  |   |
|                                | Clear cause<br>n=90 (50%)                          | "I fell about eight steps down a staircase and hit my shoulder"   |
|                                |  | "When I feel like this, it is usually tonsillitis"  |
|                                | Unclear cause<br>n=42 (23%)                        | "I think it could be a mixture of stress and bacteria"  |
|                                |  | "It is not an allergymy immune system might be<br>a bit affected because I have been travelling a<br>lot" |
|                                | <b>No cause</b><br>n=48 (27%)                      |   |
| Cure/control<br>n=138<br>(77%) | Themes   | Examples of citations   |
|                                | Clear solution                                     | "I want to go to the hospital and get stitches"   |
|                                | for cure/control                                   |   |
|                                | n=42 (23%)   | "I have tried it before; when I got penicillinI am<br>going to try to convince you to give it me again"   |
|                                | Unclear solution<br>for cure/control<br>n=96 (53%) | "I have gotten painkillers from the dentist, but<br>they are not helping; can I take Panodil as well?"    |
|                                |  | "I tried getting in contact with my GP, but no one<br>is picking up the phone"                            |
|                                |  | "Do I have to do anything about it tonight or can it wait until I call my GP tomorrow?"                   |
|                                | No solution for<br>cure/control<br>n=42 (23%)      | 2/  |
| Consequence<br>n=67<br>(37%)   | Themes   | Examples of citations   |
| · /                            | High   | "I am afraid it could be a blood clot. mv mother  |
|                                | consequence<br>n=36 (20%)                          | had that and she lost her entire leg"   |
|                                |  | "I am pregnant, can it affect the baby?"  |
|                                |  | "I read on Google, that it could be cancer"   |

| Low<br>consequence<br>n=31 (17%) | "I cannot sleep or eat anything, because of the pain"<br>"Maybe I cannot go out riding tomorrow" |
|----------------------------------|--|
| No<br>consequence<br>n=113 (63%) |  |

#### Table 2. Thematic analysis of the components of the CSM framework

#### Footnotes

**Contributorship statement:** SLT and HGJ planned the study. HGJ planned and performed the data collection. SLT extracted and analysed the data and drafted the manuscript. IE and FKL supervised and contributed substantially to the critical revision. All authors read and approved the final manuscript

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**Data sharing statement:** Additional data that are not available online can be obtained by contacting the corresponding author.

**Ethical statement:** The study was approved by the Data Protection Agency (PVH-2015-004, I-Suite nr: 04330). All participants gave informed consent. The Ethical Committee was consulted but no permission was needed (H-15016323).

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| <sup>19</sup> Lau RR, Bernard TM, Hartman KA. Further explorations of common-sense common illnesses. Health Psychology 1989;8:195–219. doi:10.1037//0278-6   | representations of 133.8.2.195        |
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#### **Tables**

|              |                    | Present stud            | lv                  | Previous stu   | Idies                             |
|--------------|--------------------|-------------------------|---------------------|--|-----------------------------------|
|              | Low<br>DOW<br>N=76 | Moderate<br>DOW<br>N=39 | High<br>DOW<br>N=65 | Farquharson et al. <sup>(10)</sup><br>(2011)<br>N=59 | Lau et al. (10<br>(1989)<br>N=887 |
| Identity     | 100                | 100                     | 100                 | 100  | 96                                |
| Timeline     | 100                | 100                     | 100                 | 44   | 49                                |
| Cause        | 82                 | 72                      | 65                  | 15   | 28                                |
| Cure/control | 78                 | 79                      | 74                  | 37   | 32                                |
| Consequence  | 33                 | 28                      | 48                  | 14   | 33                                |

#### Table 1. Prevalence (%) of components of illness representation

| Identity        | Themes                        | Examples of citations   |
|-----------------|-------------------------------|---|
| n=180<br>(100%) |                               |   |
|                 | Strong identity<br>n=56 (31%) | "I have a bladder infectionI have to pee all the timeI also had a UTI last summer"  |
|                 |                               | "I rubbed my eye and now it is red and there is   |
|                 |                               | pus it is an eye infectionI know it goes away,  |
|                 |                               | as I have had it before"  |
|                 | Medium identity<br>n=90 (50%) | "I have had genital herpes many times before,<br>but it looks differentmaybe it is just a yeast<br>infection"   |
|                 |                               | "sudden pain after I sneezedI think I might   |
|                 |                               | have punctured a lung or bruised a rib…"  |
|                 | Weak identity<br>n=34 (19%)   | "I suddenly got a severe pain in the left, lower<br>side of my abdomenI have never tried anything<br>like it beforeI cannot figure out why I am in so<br>much pain"   |
|                 |                               | "I have had two attacks of chest pain and cold<br>sweatsI do not usually feel like thisdoes not<br>feel like pain that I have tried beforeI just want<br>to know why" |
| Timeline        | <5 hours                      |   |
| (100%)          | 5-24 hours                    |   |
|                 | n=44 (24%)                    |   |

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|                                       | > <b>24 hours</b><br>n=84 (47%)               |  |
|---------------------------------------|---|--|
| <b>Cause</b><br>n=132<br>(73%)        | Themes  | Examples of citations  |
|                                       | Clear cause<br>n=90 (50%)                     | "I fell about eight steps down a staircase and h my shoulder"  |
|                                       |   | "When I feel like this, it is usually tonsillitis"   |
|                                       | Unclear cause<br>n=42 (23%)                   | "I think it could be a mixture of stress and bacteria"   |
|                                       | 0,  | "It is not an allergymy immune system might<br>a bit affected because I have been travelling a<br>lot" |
|                                       | <b>No cause</b><br>n=48 (27%)                 |  |
| <b>Cure/control</b><br>n=138<br>(77%) | Themes  | Examples of citations  |
|                                       | Clear solution                                | "I want to go to the hospital and get stitches"  |
|                                       | for cure/control<br>n=42 (23%)                | "I have tried it before; when I got penicillinI a<br>going to try to convince you to give it me again  |
|                                       | Unclear solution<br>for cure/control          | "I have gotten painkillers from the dentist, but<br>they are not helping; can I take Panodil as well   |
|                                       | 11-00 (00 %)                                  | "I tried getting in contact with my GP, but no or<br>is picking up the phone"                          |
|                                       |   | "Do I have to do anything about it tonight or car<br>wait until I call my GP tomorrow?"                |
|                                       | No solution for<br>cure/control<br>n=42 (23%) |  |
| Consequence<br>n=67<br>(37%)          | Themes  | Examples of citations  |
| <u> </u>                              | High<br>consequence<br>n=36 (20%)             | "I am afraid it could be a blood clot, my mother<br>had that and she lost her entire leg"              |
|                                       |   | "I am pregnant, can it affect the baby?"   |

|                                  | "I read on Google, that it could be cancer"  |
|----------------------------------|--|
| Low<br>consequence<br>n=31 (17%) | "I cannot sleep or eat anything, because of the pain"<br>"Maybe I cannot go out riding tomorrow" |
| No<br>consequence<br>n=113 (63%) |  |





Figure 1. Flowchart of calls included



Figure 2. Prevalence (%) of components of illness representation in present study



Figure 3. Interrelation between DOW and the components of the CSM framework

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BMJ Open

## **BMJ Open**

#### Relation between illness representation and self-reported degree-of-worry in patients calling out-of-hours services: a mixed methods study in Copenhagen, Denmark

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| <b>Primary Subject<br/>Heading</b> : | Emergency medicine   |
| Secondary Subject Heading:           | Qualitative research, Patient-centred medicine   |
| Keywords:                            | illness representation, degree-of-worry, out-of-hours services, triage   |
|                                      |  |



# Relation between illness representation and self-reported degree-of-worry in patients calling out-of-hours services: a mixed methods study in Copenhagen, Denmark

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#### ABSTRACT

#### **Objectives:**

To examine the relation between patients' illness representations, presented in telephone consultation to out-of-hours (OOH) services, and self-reported degree-of-worry (DOW), as a measure of self-evaluated urgency. If a clear relation is found, incorporating DOW during telephone triage could aid the triage process, potentially increasing patient safety.

#### Design:

A convergent parallel mixed methods design with quantitative data; DOW and qualitative data; recorded telephone consultations. Thematic analysis of the qualitative data was used to explore the content of the quantitative scaled DOW, using the Common Sense Model of Self-Regulation (CSM).

#### Setting:

A convenience sampling of calls to the OOH services in Copenhagen, Denmark, during three days was included in the study.

#### Participants:

Calls from adults (≥15 years of age) concerning somatic illness during the data collection period were eligible for inclusion. Calls made on behalf of another person, calls concerning perceived life-threatening illness or calls regarding logistical/practical problems were excluded, resulting in analysis of 180 calls.

#### **Results:**

All five components of the CSM framework, regardless of DOW, were present in the data. All callers referred to identity and timeline and were least likely to refer to consequence (37%). Through qualitative analysis, themes were defined. Callers with a strong identity, illness duration of less than 5 hours, clear cause and solution for cure/control were more likely to present a low DOW. Callers with a medium identity, illness duration of more than 24 hours and a high consequence were more likely to present a high DOW.

#### Conclusion:

This study suggests a relation between a patient's illness representation and self-evaluation of urgency. Incorporating a patient's DOW during telephone triage could aid the triage process in determining urgency and type of health care needed, potentially increasing patient safety. Research on patient outcome after DOW-assisted triage is needed before implementation of the DOW scale is recommended.

#### Article summary:

#### Strengths and limitations of this study

- Use of mixed methods approach in this study gave an in-depth insight and enabled a thorough analysis and understanding of the illness representation of patients to an OOH service.
- Patients' presentation of their illness representation and reported self-evaluation of their DOW were obtained at the actual time of seeking help and therefore, not influenced by recall bias.
- DOW was not uniformly obtained at a specific time within the consultation and responses were both spontaneous and/or prompted by the call-handler, which is representative of real-life calls to OOH services.
- Use of the NVivo V.11 software and researcher triangulation ensures that the coding of the data is available for independent analysis and less subject to personal bias.
- Due to the limited size of the study population, there is a lack of statistical power; however, the results show clear trends and relations, which give direction for future research to strengthen evidence in this new area.



#### INTRODUCTION

Telephone triage within out-of-hours (OOH) service is recognised as a mean to reduce pressure and overcrowding of emergency departments (ED) and OOH clinics.<sup>1</sup> It aims to assess the urgency of a patient's medical condition in order to determine the correct type of health care needed, thus ensuring patient safety. However, due to the lack of non-verbal cues in telephone consultations, assessing urgency is more challenging than face-to-face consultations.<sup>2</sup> Studies show that the quality of telephone triage improves with communication between patient and health professional being patient-centred rather than disease-centred<sup>3</sup> and that non-normative symptom description and poor communication contribute to under-triage.<sup>4</sup> Triage tools, e.g. computerised decision support systems are used to aid the triage process<sup>5</sup>; however, these tools focus on medical information and less on psychosocial or affective information.<sup>6</sup>

Patients' perception of urgency has previously been examined, whereby, ED physicians' and the patients' assessment of the severity of symptoms were compared.<sup>78</sup> These studies found that patients' perception of urgency can be used as a rough guide to predict the need for hospitalisation.<sup>9</sup> Furthermore, it has been suggested that patients expressing a potential need for hospitalisation should be thoroughly examined for possible severe illness.<sup>10</sup> Previous studies have also shown that patient anxiety or worry about a health threat is a major factor in urgent care decision-making.<sup>11 12</sup> Therefore, the measure of a patient's anxiety or worry about an acute health threat reflects the patient's self-evaluation of urgency. A self-reported verbal ten-point NRS measuring anxiety in patients (1=minimal anxiety to 10=maximal anxiety) has previously been used in several studies in acute care settings.<sup>13</sup> The anxiety observed in these patients was regarded as acute in relation to the immediate health threat and not due to an underlying psychiatric disease.<sup>14</sup> This scale has not been validated. However, as anxiety is a completely subjective symptom, it was felt that a subjective scoring system was acceptable. The feeling of anxiety in this setting is synonymous to worry. In this study, we measured the patient's selfevaluation of urgency, defined as degree-of-worry (DOW), by using a verbal 10-point numerical rating scale (NRS) (1=minimal worry to 10=maximal worry). A previous study shows that callers to OOH services are able to rate their DOW, and that the DOW scale is feasible for large-scale studies.<sup>15</sup> We used the word *worry* and not *anxiety*, as we felt anxiety may be associated with physical symptoms, such as elevated heart rate or shortness of breath, while worry is more of a cognitive nature.<sup>16</sup>

The Common-Sense Model of Self-Regulation (CSM), by Leventhal<sup>17</sup> is a widely recognized theoretical framework, which can be used to describe how a patient cognitively and emotionally addresses a health threat, based on experienced symptoms. The patient's perception is based on prior experience, personal beliefs, discussions with others and cultural understandings.<sup>18</sup> The CSM is a parallel processing model, with one arm representing the cognitive processing aspects and the other arm representing the emotional processing aspects. Together they make up a patients' illness representation.<sup>19</sup> The cognitive arm can be categorized into five components: 1) *identity*: symptoms or name/label of the health threat, 2) *timeline*: duration of the health threat 3) *cause*: factors that are responsible for the health threat, 4) *cure or control*: whether the health threat can be cured or controlled and 5) *consequence*: of the health threat.<sup>18</sup> The patients' understanding of their illness representation influences how they present their health issue to a health care provider and this may in turn influence the care they receive.<sup>20</sup> In previous studies, it has been shown that

 the five components of the CSM framework account for a large proportion of the presentations patients make when contacting OOH services<sup>21</sup> and serve as an appropriate framework for understanding the worry experiences of primary health care patients.<sup>22</sup>

The aim of this paper is to examine the relation between a patient's illness representation, as presented in telephone consultation to an OOH service call handler, and the self-reported DOW as a measure of self-evaluated urgency. If there is a relation, incorporating a patient's DOW as an additional tool in the telephone triage process could aid determination of urgency and type of health care needed, potentially increasing patient safety.

#### METHOD

#### Design

A convergent parallel mixed methods design with simultaneously collected data was used. This design allows for the transformation of one type of result to another (e.g. themes into counts).<sup>23</sup> Quantitative data consisted of DOW and qualitative data of recorded telephone consultations. Deductive thematic analysis of the qualitative data was conducted and used to explore the content of the quantitatively scaled DOW, using the framework of the CSM theory.

#### Setting

The OOH services and the Emergency Medical Services, Copenhagen, the Capital Region of Denmark, are integrated in one organisation and can be reached through two telephone numbers; 112 for life-threatening emergencies and 1813 for acute, non-emergent medical calls. The Medical Helpline 1813 is available from 4pm to 8am on weekdays and around the clock on weekends and holidays. Individuals may also call 1813 for a referral to an emergency department, if they cannot get in touch with their general practice (GP) during regular working hours. All access to acute care is pre-assessed by telephone triage. Annually, approximately one million calls are handled by call handlers (nurses/physicians) who triage the caller to self-care, a general practitioner, face-to-face assessment/consultation at a hospital, home visit or direct hospitalisation.<sup>24 25</sup>

#### **Data collection**

A total of 261 callers to the OOH services, The Medical Helpline 1813, during a three-day time period were approached for inclusion in this study. As a new rating scale was being implemented by the call handlers, it was considered, that this was a reasonable length of time. All calls from adults ( $\geq$ 15 years of age) concerning somatic illness were deemed eligible for inclusion. Calls made on behalf of another person, including children (n=16) were excluded, in order to have a study population exclusively describing personal symptoms. Furthermore, calls in which consent was not granted (n=1), calls in which the call handler failed to ask study questions (n=19), calls in which there were technical problems with the call recording (n=33) and repeat callers (n=12) were also excluded. This resulted in a convenience sample of a total of 180 calls. Data were collected for three consecutive days: Wednesday 20<sup>th</sup> April and Thursday 21<sup>st</sup> April (4pm to 10pm) and Friday 22<sup>nd</sup> April (8am to 4pm) 2016 (a bank holiday), 2016. The study was approved by the Data Protection Agency, Denmark.

#### Data sources

Data consisted of two parallel strands – the quantitative scaled DOW and illness representation presented by the callers – both derived from the recorded telephone consultations. Two experienced call handlers were first asked to assess and recommend question phrasing for data collection. All call handlers participated in data collection and received instructions on procedure, inclusion criteria, study focus and voluntary caller participation. Based on the recommendations, call handlers were instructed to ask the following questions in each call: "What is your reason for calling in today?", "How long have you been experiencing these symptoms?" and "On a scale from 1-10, how worried are you?". Additional questions were asked at the call handlers' discretion as they deemed relevant and the caller was invited to participate in the study, giving verbal informed consent. Data were collected throughout the course of the consultation. Calls in which the caller failed to provide a number reflecting their DOW (n=10), were assessed by two researchers and using the intensity verbal descriptors (see table 1, Duncan *et al*<sup>26</sup>) assigned a numeric value (1 to 10). If not concurrent, a consensus was reached through discussion. The intensity verbal descriptors used, describe the intensity of pain and not worry. However, as both pain and worry are subjective, it was felt, that in these few cases, the intensity descriptors for pain were an adequate tool.

#### Patient and public involvement

The development of the research aim, design, recruitment, conduct and outcome measures in this study were not based on patients' involvement. The results of this study will not automatically be disseminated to study participants. However, participants can request information regarding this study.

#### ANALYSIS

The recorded telephone consultations were transcribed in NVivo V.11 and DOW were attached to each call as attributes. According to the information given by the callers, symptom duration (timeline) was categorised into three groups: less than 5 hours, 5 to 24 hours and more than 24 hours. The remaining qualitative data were deductively coded according to the last four components of the CSM framework, by the main author. For the purpose of simplicity, the results were then sub-grouped into: low DOW (DOW 1 to 4), moderate DOW (DOW 5 and 6) and high DOW (DOW 7 to 10). Furthermore, the results were compared to two previous studies: Farquharson *et al*<sup>21</sup> and Lau *et al*.<sup>27</sup>

#### Qualitative data analysis

The qualitative data were created by coding the transcripts deductively according to the four components of the CSM framework (identity, cause, cure/control and consequence), while disregarding the DOW value. For each of the four components, data were clustered and patterns identified. Three themes within each component were derived from these patterns and each theme was recoded, as described by Braun and Clarke.<sup>28</sup> The patterns and thereby derived theme definitions, were discussed and agreed upon with a second researcher, using 50% of the study

data. The remaining data were rechecked and recoded if necessary, by the main researcher, according to the agreed theme definitions.

#### Mixed methods analysis

All 180 calls were grouped according to themes in each of the five CSM components and listed according to DOW (1-10). For each theme, the quantiles (Q1-Q3) and median were calculated and a box and whisker plot created.

#### RESULTS

#### Participants

A total of 261 callers to the OOH services during the three-day time period were approached for inclusion. Of these, 81 callers were excluded, based on the exclusion criteria, leaving a total of 180 callers to be included in this study. Due to this limited size of the study population, there is a lack of statistical power. The nature of the calls was as follows: acute illness (n = 120), injury (n = 37), exacerbation of chronic disease (n = 15), other (n = 7), and undetermined (n = 1), which is representative for calls to the OOH services.<sup>29</sup> (See table 1.)

| DOW                 | Low DOW<br>(1-4)      | Moderate DOW<br>(5-6) | High DOW<br>(7-10) |
|---------------------|-----------------------|-----------------------|--------------------|
| Total study callers | 76                    | 39                    | 65                 |
| Women               | 43 (57%) <sup>i</sup> | 24 (62%)              | 47 (72%)           |
| Men                 | 33 (43%)              | 15 (38%)              | 18 (28%)           |
| Age 15-20 years     | 4 (5%)                | 5 (13%)               | 10 (15%)           |
| Age 21-40 years     | 46 (61%)              | 19 (49%)              | 26 (40%)           |
| Age 41-65 years     | 19 (25%)              | 13 (33%)              | 21 (32%)           |
| Age >65 years       | 7 (9%)                | 2 (5%)                | 8 (12%)            |

#### Table 1. Participant demographics

<sup>1</sup>Percentages of total callers in each DOW group.

#### Quantitative findings according to the CSM framework

All callers referred to identity, as well as duration (timeline) of their symptoms. Callers with a low DOW were more likely to mention a cause for their illness (82%) than other callers, whereas, reference to cure/control was similar (78%, 79% and 74%) in all three DOW sub-groups. Callers in all three DOW sub-groups were least likely to refer to consequence compared to the other four CSM components; however, callers with a high DOW were more likely to refer to a consequence (48%) of their illness than callers with moderate (28%) or low DOW (33%). (See figure 1.)

#### (Placement of figure 1.)

#### Qualitative findings

#### Identity

Callers' referrals to the identity of their perceived health threat were divided into three themes: Strong identity; use of a definitive label or diagnosis, reference to a previous identical experience, reference to a known condition and/or expression of certainty (n=56), *medium identity*; hypothesis of label or diagnosis, reference to a previous similar, but not identical experience and/or expression of near certainty (n=90) and *weak identity*; no mention of label or diagnosis, no reference to a previous experience, reference to an unknown condition and/or expression of uncertainty (n=34).

#### Timeline

Fifty-two callers described symptoms which had lasted *less than 5 hours*, 44 callers described symptoms which had lasted *between 5 and 24 hours* and 84 callers described symptoms which had lasted *more than 24 hours*.

#### Cause

A possible cause of symptoms or illness was reported by 132 callers (73%). The reported causes were divided into the following three themes: *clear cause*; expression of certainty (n=90); *unclear cause*; a hypothesis suggested or expression of uncertainty (n=42); and *no mention of cause* (n=48).

#### Cure/control

Reference pertaining to a cure or control related to their symptoms or illness was made by 138 callers (77%). These were divided in to the following three themes: *clear solution for cure/control*; specific request for treatment (n=42), *unclear solution for cure/control*; suggestion for treatment or had attempted self-treatment with little or no effect (n=96), and *no mention of cure/control* (n=42).

#### Consequence

Reference to a consequence of their symptoms or illness was made by 67 callers (37%). These were categorized into the following three themes: *high consequence*; potentially long-term or life-threatening consequences and consequences severely affecting work or social life (n=36), *low consequence;* short-term consequences, consequences affecting immediate daily life or mildly affecting work or social life (n=31) and *no mention of consequence* (n=113).

(See table 2 for examples of citations of each theme. Citations were chosen to represent the breadth of definition of each theme.)

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| Identity        | Themes                  | Examples of citations                                 |
|-----------------|-------------------------|---|
| n=180<br>(100%) |                         |   |
| (10070)         | Strong identity         | "I have a bladder infectionI have to pee all the      |
|                 | n=56 (31%)              | timeI also had a UTI last summer"                     |
|                 |                         | "I rubbed my eye and now it is red and there is       |
|                 |                         | pus it is an eye infectionI know it goes away,        |
|                 |                         | as I have had it before"                              |
|                 |                         | "My right big toe is swollen, the area next to the    |
|                 |                         | nail is red and infected, I can press pus out"        |
|                 | Medium                  | "I have had genital herpes many times before, but     |
|                 | identity                | it looks differentmaybe it is just a yeast            |
|                 | 11-90 (50 %)            |   |
|                 |                         | "sudden pain after I sneezedI think I might           |
|                 |                         | have punctured a lung or bruised a rib"               |
|                 |                         | "I have a favor and my threat hurte. I think I'm      |
|                 |                         | sick it's usually a throat infection "                |
|                 | Weak identity           | "I suddenly got a severe pain in the left lower side  |
|                 | n=34 (19%)              | of my abdomenI have never tried anything like it      |
|                 |                         | beforeI cannot figure out why I am in so much         |
|                 |                         | pain  |
|                 |                         | "I have had two attacks of chest pain and cold        |
|                 |                         | sweatsI do not usually feel like thisdoes not         |
|                 |                         | feel like pain that I have tried beforeI just want to |
|                 |                         | know why"   |
|                 |                         | "I feel really bad; have had a fever for 3-4 days and |
|                 |                         | I'm coughing a lot. Yesterday, I had the shakes and   |
|                 |                         | I threw up"   |
| Timeline        | <5 hours                | "I just fell and cut my forehead and it is            |
| n=180           | n=52 (29%)              | bleeding"   |
| (100%)          | 5-24 hours              | "I started feeling sick this morning, but I still     |
|                 | n=44 (24%)              | decided to go to work"                                |
|                 | >24 hours<br>n=84 (47%) | "It's been going on for a few days now"               |
| 0               | <b>T</b>                |   |
| n=132           | Inemes                  | Examples of citations                                 |
| (73%)           |                         |   |
| <u> </u>        | Clear cause             | "I fell about eight steps down a staircase and hit my |
|                 | n=90 (50%)              | shoulder"   |

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|                              |   | "When I feel like this, it is usually tonsillitis"   |
|                              |   | "After skatingpain in my leg muscle strain seems very logical"   |
|                              | Unclear cause<br>n=42 (23%)                             | "I think it could be a mixture of stress and bacteria"   |
|                              |   | "It is not an allergymy immune system might be a bit affected because I have been travelling a lot"          |
|                              |   | "It looks like hives, but I do not have any allergies"   |
|                              | <b>No cause</b><br>n=48 (27%)                           |  |
| Cure/control                 | Themes  | Examples of citations  |
| n=138<br>(77%)               |   | C_   |
|                              | Clear solution  | "I want to go to the hospital and get stitches"  |
|                              | for cure/control  | "I have tried it before when I get perioilling I am  |
|                              | 11-42 (23%)   | going to try to convince you to give it me again"  |
|                              |   | "I have spoken to my husband, who is a doctor,<br>and he believes I need to be seen by an eye<br>specialist" |
|                              | Unclear<br>solution for                                 | "I have gotten painkillers from the dentist, but they are not helping; can I take Panodil as well?"          |
|                              | n=96 (53%)  | "I tried getting in contact with my GP, but no one is picking up the phone"                                  |
|                              |   | "Do I have to do anything about it tonight or can it wait until I call my GP tomorrow?"                      |
|                              |   |  |
|                              | No solution for<br>cure/control<br>n=42 (23%)           |  |
| Consequence<br>n=67<br>(37%) | No solution for<br>cure/control<br>n=42 (23%)<br>Themes | Examples of citations  |

|                                  | "I am pregnant, can it affect the baby?"              |
|----------------------------------|---|
|                                  | "I read on Google, that it could be cancer"           |
| Low<br>consequence<br>n=31 (17%) | "I cannot sleep or eat anything, because of the pain" |
|                                  | "Maybe I cannot go out riding tomorrow"               |
|                                  | "I have to travel for work tomorrow"                  |
| No<br>consequence<br>n=113 (63%) |   |

#### Table 2. Thematic analysis of the components of the CSM framework

#### Mixed methods findings

Study callers with a *medium identity* were more likely to have the highest DOWs, while callers with a *strong identity* generally had a lower DOW and callers with a *weak identity* generally had more moderate DOWs. Callers whose illness had lasted *less than 5 hours* were more likely to have a low to moderate DOW, whereas callers whose illness had lasted *more than 24 hours* were more likely to have a more moderate to high DOW. Callers with a *clear cause* for their illness and a *clear solution for cure/control* were more likely to have a low DOW and finally, callers who mentioned a *high consequence* to their illness were more likely to have a high DOW. (See figure 2.)

#### (Placement of figure 2.)

#### DISCUSSION

#### Summary of main findings

Using the five components of the CSM framework, as described by Leventhal<sup>18</sup>, our analysis demonstrated that callers presenting their illness to OOH services to a large extent referred to all five components, regardless of their self-evaluated DOW. All callers referred to identity and timeline and callers were least likely to refer to consequence.

A low DOW was more present within the group of callers who had a strong illness identity, illness duration of less than five hours, a clear cause and a clear solution. Callers who presented a medium or weak illness identity, illness duration of more than 24 hours and, an unclear cause and unclear solution and a perception of high consequence were more likely to present a higher DOW.

#### Strengths and limitations of this study

The main strength of this study was the use of mixed methods approach, which gave an in-depth insight and enabled a thorough analysis and understanding of the illness representation of patients to an OOH service. In addition, patients' illness representation and reported self-evaluation of DOW were obtained in real time, as the callers were seeking help. Findings were, therefore, not

influenced by recall bias. DOW was not uniformly obtained at a specific time within the consultation. Therefore, the consultation itself could influence the patient's DOW and the patient's DOW could influence the consultation. This, however, is representative of real-life calls to OOH services and how DOW can be used as a potential triage tool. Use of the NVivo V.11 software and researcher triangulation ensure that the coding of the data is available for independent analysis and less subject to personal bias. Due to the short duration of data collection, the size of the study population was limited, resulting in a lack of statistical power. However, irrespective of this limitation, the analyses of the results, using the mixed methods approach, show a distinct trend and relation between DOW as a measure of patient-evaluated urgency and their illness representation.

#### Comparison with existing literature

The results of the quantitative data can be compared to work done by Farquharson *et al*<sup>21</sup> and Lau *et al*.<sup>27</sup> (See table 3.) Participants in both studies and in all three DOW sub-groups in the present study mentioned factors pertaining to all five components of the CSM framework. Farquharson *et al*, however, solely based their data on information that callers volunteered, without call handler prompting, but suggested that it may be necessary for call handlers to prompt remaining components to obtain a comprehensive understanding of patients' representations of illness. In this study, all information from the caller was coded, including information prompted by the call handler, thus the prevalence in each of the five CSM components was greater compared to those found by Farquharson et al. The method used in this study provides a more complete portrayal of the caller's illness representation and is more representative of real-life calls to OOH services.

|              |                    | Present study           |                     | Previous stu   | ıdies   |
|--------------|--------------------|-------------------------|---------------------|--|---|
|              | Low<br>DOW<br>N=76 | Moderate<br>DOW<br>N=39 | High<br>DOW<br>N=65 | Farquharson <i>et al</i> <sup>(21)</sup><br>(2011)<br>N=59 | Lau <i>et al</i> <sup>(27)</sup><br>(1989)<br>N=887 |
| Identity     | 100                | 100                     | 100                 | 100  | 96  |
| Timeline     | 100                | 100                     | 100                 | 44   | 49  |
| Cause        | 82                 | 72                      | 65                  | 15   | 28  |
| Cure/control | 78                 | 79                      | 74                  | 37   | 32  |
| Consequence  | 33                 | 28                      | 48                  | 14   | 33  |

## Table 3. Prevalence (%) of components of illness representation

#### Relevance of this study: possible implications for health care providers and policy makers

This study suggests a relation between a patient's illness representation, as presented telephonically to an OOH services call handler, and the self-evaluation of urgency, defined as DOW. This is a new area of research and this study gives direction for future research to further strengthen the evidence. Research on coherence between patient DOW, call handlers', ED and GP physicians' assessment of urgency, both prospectively and retrospectively will strengthen the basis for potential use of DOW as a triage tool. Incorporating DOW as an additional tool in the telephone triage process could potentially aid in the determination of urgency and the type of health care needed, thus increasing patient safety.

#### Figure legends

Figure 1. Prevalence (%) of components of illness representation in present study

Figure 2. Relation between DOW and the components of the CSM framework

#### **Footnotes**

**Contributorship statement:** SLT and HGJ planned the study and discussed and agreed upon theme definitions in the qualitative analysis. HGJ planned and performed the data collection. SLT extracted and analysed the data and drafted the manuscript. IE and FKL supervised and contributed substantially to the critical revision. All authors read and approved the final manuscript.

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**Data sharing statement:** Additional data that are not available online can be obtained by contacting the corresponding author.

**Ethical statement:** The study was approved by the Data Protection Agency (PVH-2015-004, I-Suite nr.: 04330). All participants gave informed consent. The Ethical Committee was consulted but no permission was needed (H-15016323).

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Keywords: illness representation, degree-of-worry, out-of-hours services, triage

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<text><text><text>



Figure 1. Prevalence (%) of components of illness representation in present study

61x21mm (300 x 300 DPI)

None



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#### STROBE (Strengthening The Reporting of OBservational Studies in Epidemiology) Checklist

A checklist of items that should be included in reports of observational studies. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

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| Section and Item     | Item<br>No. | Recommendation  | Reported o<br>Page No. |
|----------------------|-------------|---|------------------------|
| itle and Abstract    | 1           | (a) Indicate the study's design with a commonly used term in the title or the               | U                      |
|                      |             | abstract  |                        |
|                      |             | (b) Provide in the abstract an informative and balanced summary of what was                 |                        |
|                      |             | done and what was found   |                        |
| ntroduction          |             |   | I                      |
| Jackground/Rationale | 2           | Explain the scientific background and rationale for the investigation being                 |                        |
|                      |             | reported  |                        |
| Dbjectives           | 3           | State specific objectives, including any prespecified hypotheses                            |                        |
| //ethods             |             |   |                        |
| tudy Design          | 4           | Present key elements of study design early in the paper                                     |                        |
| etting               | 5           | Describe the setting, locations, and relevant dates, including periods of                   |                        |
|                      |             | recruitment, exposure, follow-up, and data collection                                       |                        |
| articipants          | 6           | (a) Cohort study—Give the eligibility criteria, and the sources and methods of              |                        |
|                      |             | selection of participants. Describe methods of follow-up                                    |                        |
|                      |             | <i>Case-control study</i> —Give the eligibility criteria, and the sources and methods of    |                        |
|                      |             | case ascertainment and control selection. Give the rationale for the choice of              |                        |
|                      |             | cases and controls  |                        |
|                      |             | <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of |                        |
|                      |             | selection of participants   |                        |
|                      |             | (b) Cohort study—For matched studies, give matching criteria and number of                  |                        |
|                      |             | exposed and unexposed   |                        |
|                      |             | <i>Case-control study</i> —For matched studies, give matching criteria and the number       |                        |
|                      |             | of controls per case  |                        |
| /ariables            | 7           | Clearly define all outcomes, exposures, predictors, potential confounders, and              |                        |
|                      | 1           | effect modifiers. Give diagnostic criteria, if applicable                                   |                        |

| Section and Item       | ltem<br>No. | Recommendation   | Reporte<br>Page N |
|------------------------|-------------|--|-------------------|
| Data Sources/          | 8*          | For each variable of interest, give sources of data and details of methods of                        |                   |
| Measurement            |             | assessment (measurement). Describe comparability of assessment methods if                            |                   |
|                        |             | there is more than one group   |                   |
| Bias                   | 9           | Describe any efforts to address potential sources of bias  |                   |
| Study Size             | 10          | Explain how the study size was arrived at  |                   |
| Quantitative Variables | 11          | Explain how quantitative variables were handled in the analyses. If applicable,                      |                   |
|                        |             | describe which groupings were chosen and why   |                   |
| Statistical Methods    | 12          | (a) Describe all statistical methods, including those used to control for                            |                   |
|                        |             | confounding  |                   |
|                        |             | (b) Describe any methods used to examine subgroups and interactions                                  |                   |
|                        |             | (c) Explain how missing data were addressed  |                   |
|                        |             | (d) Cohort study—If applicable, explain how loss to follow-up was addressed                          |                   |
|                        |             | <i>Case-control study</i> —If applicable, explain how matching of cases and controls was             |                   |
|                        |             | addressed  |                   |
|                        |             | <i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of           |                   |
|                        |             | sampling strategy  |                   |
|                        |             | (e) Describe any sensitivity analyses  |                   |
| Results                |             |  | 1                 |
| Participants           | 13*         | (a) Report numbers of individuals at each stage of study—eg numbers potentially                      |                   |
|                        |             | eligible, examined for eligibility, confirmed eligible, included in the study,                       |                   |
|                        |             | completing follow-up, and analysed   |                   |
|                        |             | (b) Give reasons for non-participation at each stage   |                   |
|                        |             | (c) Consider use of a flow diagram   |                   |
| Descriptive Data       | 14*         | (a) Give characteristics of study participants (eg demographic, clinical, social) and                |                   |
|                        |             | information on exposures and potential confounders   |                   |
|                        |             | (b) Indicate number of participants with missing data for each variable of interest                  |                   |
|                        |             | (c) <i>Cohort study</i> —Summarise follow-up time (eg, average and total amount)                     |                   |
| Outcome Data           | 15*         | <i>Cohort study</i> —Report numbers of outcome events or summary measures over time                  |                   |
|                        |             | <i>Case-control study</i> —Report numbers in each exposure category, or summary measures of exposure |                   |
|                        |             | Cross-sectional study—Report numbers of outcome events or summary measures                           |                   |

| 1<br>2         | Section and Item             | ltem<br>No. | Recommendation   | Reported on<br>Page No. |  |  |
|----------------|------------------------------|-------------|--|-------------------------|--|--|
| 3              | Main Results                 | 16          | (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates                                  |                         |  |  |
| 4              |                              |             | and their precision (eg, 95% confidence interval). Make clear which confounders                                  |                         |  |  |
| 5<br>6         |                              |             | were adjusted for and why they were included   |                         |  |  |
| 7<br>8         |                              |             | (b) Report category boundaries when continuous variables were categorized  |                         |  |  |
| 9<br>10<br>11  |                              |             | (c) If relevant, consider translating estimates of relative risk into absolute risk for a meaningful time period |                         |  |  |
| 12<br>13<br>14 | Other Analyses               | 17          | Report other analyses done—eg analyses of subgroups and interactions, and sensitivity analyses                   |                         |  |  |
| 15<br>16<br>17 | Discussion                   |             |  |                         |  |  |
| 18<br>19       | Key Results                  | 18          | Summarise key results with reference to study objectives   |                         |  |  |
| 20             | Limitations                  | 19          | Discuss limitations of the study, taking into account sources of potential bias or                               |                         |  |  |
| 21<br>22       |                              |             | imprecision. Discuss both direction and magnitude of any potential bias  |                         |  |  |
| 23             | Interpretation               | 20          | Give a cautious overall interpretation of results considering objectives, limitations,                           |                         |  |  |
| 24<br>25       |                              |             | multiplicity of analyses, results from similar studies, and other relevant evidence                              |                         |  |  |
| 26<br>27       | Generalisability             | 21          | Discuss the generalisability (external validity) of the study results  |                         |  |  |
| 28<br>29       | Other Information            |             |  |                         |  |  |
| 30<br>31       | Funding                      | 22          | Give the source of funding and the role of the funders for the present study and, if                             |                         |  |  |
| 32             |                              |             | applicable, for the original study on which the present article is based   |                         |  |  |
| 33<br>34       |                              |             |  |                         |  |  |
| 35             | *Give information separation | ately for   | cases and controls in case-control studies and, if applicable, for exposed and unexpos                           | ed groups in            |  |  |
| 36<br>37       | cohort and cross-section     | al studie   | es.  |                         |  |  |
| 38             | Once you have complete       | ed this c   | hecklist, please save a copy and upload it as part of your submission. DO NOT includ                             | e this                  |  |  |
| 39<br>40       | checklist as part of the r   | nain ma     | nuscript document. It must be uploaded as a separate file.   |                         |  |  |
| 41             | •                            |             |  |                         |  |  |
| 42             |                              |             |  |                         |  |  |
| 43             |                              |             |  |                         |  |  |

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## **BMJ Open**

#### Relation between illness representation and self-reported degree-of-worry in patients calling out-of-hours services: a mixed methods study in Copenhagen, Denmark

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|--------------------------------------|--|
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| <b>Primary Subject<br/>Heading</b> : | Emergency medicine   |
| Secondary Subject Heading:           | Qualitative research, Patient-centred medicine   |
| Keywords:                            | illness representation, degree-of-worry, out-of-hours services, triage   |
|                                      |  |



# Relation between illness representation and self-reported degree-of-worry in patients calling out-of-hours services: a mixed methods study in Copenhagen, Denmark

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#### ABSTRACT

#### **Objectives:**

To examine the relation between patients' illness representations, presented in telephone consultation to out-of-hours (OOH) services, and self-reported degree-of-worry (DOW), as a measure of self-evaluated urgency. If a clear relation is found, incorporating DOW during telephone triage could aid the triage process, potentially increasing patient safety.

#### Design:

A convergent parallel mixed methods design with quantitative data; DOW and qualitative data; recorded telephone consultations. Thematic analysis of the qualitative data was used to explore the content of the quantitative scaled DOW, using the Common Sense Model of Self-Regulation (CSM).

#### Setting:

A convenience sampling of calls to the OOH services in Copenhagen, Denmark, during three days was included in the study.

#### Participants:

Calls from adults (≥15 years of age) concerning somatic illness during the data collection period were eligible for inclusion. Calls made on behalf of another person, calls concerning perceived life-threatening illness or calls regarding logistical/practical problems were excluded, resulting in analysis of 180 calls.

#### **Results:**

All five components of the CSM framework, regardless of DOW, were present in the data. All callers referred to identity and timeline and were least likely to refer to consequence (37%). Through qualitative analysis, themes were defined. Callers with a strong identity, illness duration of less than 24 hours, clear cause and solution for cure/control seemed to present a lower DOW. Callers with a medium identity, illness duration of more than 24 hours and a high consequence seemed to present a higher DOW.

#### Conclusion:

This study suggests a relation between a patient's illness representation and self-evaluation of urgency. Incorporating a patient's DOW during telephone triage could aid the triage process in determining urgency and type of health care needed, potentially increasing patient safety. Research on patient outcome after DOW-assisted triage is needed before implementation of the DOW scale is recommended.

#### Article summary:

#### Strengths and limitations of this study

- Use of mixed methods approach in this study gave an in-depth insight and enabled a thorough analysis and understanding of the illness representation of patients to an OOH service.
- Patients' presentation of their illness representation and reported DOW were obtained at the actual time of seeking help and therefore, not influenced by recall bias.
- DOW was not uniformly obtained at a specific time within the consultation and responses were both spontaneous and/or prompted by the call-handler, which is representative of real-life calls to OOH services.
- Use of the NVivo V.11 software and researcher triangulation ensures that the coding of the data is available for independent analysis and less subject to personal bias.
- Due to the limited size of the study population, there is a lack of statistical power; however, the results show clear trends and relations, which give direction for future research to strengthen evidence in this new area.



#### INTRODUCTION

Telephone triage within out-of-hours (OOH) service is recognised as a mean to reduce pressure and overcrowding of emergency departments (ED) and OOH clinics.<sup>1</sup> It aims to assess the urgency of a patient's medical condition in order to determine the correct type of health care needed, thus ensuring patient safety. However, due to the lack of non-verbal cues in telephone consultations, assessing urgency is more challenging than face-to-face consultations.<sup>2</sup> Studies show that the quality of telephone triage improves with communication between patient and health professional being patient-centred rather than disease-centred<sup>3</sup> and that non-normative symptom description and poor communication contribute to under-triage.<sup>4</sup> Triage tools, e.g. computerised decision support systems are used to aid the triage process<sup>5</sup>; however, these tools focus on medical information and less on psychosocial or affective information.<sup>6</sup>

Patients' perception of urgency has previously been examined, comparing ED physicians' and the patients' assessment of the severity of symptoms.<sup>78</sup> These studies found that patients' perception of urgency can be used as a rough guide to predict the need for hospitalisation.<sup>9</sup> Furthermore, it has been suggested that patients expressing a potential need for hospitalisation should be thoroughly examined for possible severe illness.<sup>10</sup> Previous studies have also shown that patients' anxiety or worry about a health threat is a major factor in urgent care decision-making<sup>11 12</sup> and that worry is the most important motive for patients contacting OOH services.<sup>13</sup> Therefore, the measure of a patient's worry about an acute health threat reflects the patient's self-evaluation of urgency. A self-reported verbal ten-point numerical rating scale (NRS) measuring anxiety in patients (1=minimal anxiety to 10=maximal anxiety) has previously been used in several studies in acute care settings.<sup>14</sup> The anxiety observed in these patients was regarded as acute in relation to the immediate health threat and not due to an underlying psychiatric disease, thus, the feeling of anxiety in this setting was synonymous to worry.<sup>15</sup> This scale has not been validated. However, as anxiety is a subjective symptom, a subjective scoring system was deemed acceptable. A previous study showed that callers to OOH services were able to rate their degree-of-worry (DOW), using a verbal 10-point NRS (1=minimal worry to 10=maximal worry) as a measure of their self-evaluation of urgency. It was also shown that the DOW scale is feasible for use in large-scale studies.<sup>16</sup>

The Common-Sense Model of Self-Regulation (CSM), by Leventhal<sup>17</sup> is a widely recognized theoretical framework, which can be used to describe how a patient cognitively and emotionally addresses a health threat, based on experienced symptoms. The patient's perception is based on prior experience, personal beliefs, discussions with others and cultural understandings.<sup>18</sup> The CSM is a parallel processing model, with one arm representing the cognitive processing aspects and the other arm representing the emotional processing aspects. Together they make up a patient's illness representation.<sup>19</sup> The cognitive arm can be categorized into five components: 1) *identity*: symptoms or name/label of the health threat, 2) *timeline*: duration of the health threat 3) *cause*: factors that are responsible for the health threat, 4) *cure or control*: whether the health threat can be cured or controlled and 5) *consequence*: of the health threat.<sup>17</sup> The patients' understanding of their illness representation influences how they present their health issue to a health care provider and this may in turn influence the care they receive.<sup>20</sup> In previous studies, it has been shown that the five components of the CSM framework account for a large proportion of the presentations patients make when contacting OOH services<sup>21</sup> and serve as an appropriate framework for understanding the worry experiences of primary health care patients.<sup>22</sup>

The aim of this paper is to examine the relation between a patient's illness representation, as presented in telephone consultation to an OOH service call handler, and the self-reported DOW as a measure of self-evaluated urgency. If there is a relation, incorporating a patient's DOW as an additional tool in the telephone triage process could aid determination of urgency and type of health care needed, potentially increasing patient safety.

#### METHOD

#### Design

A convergent parallel mixed methods design with simultaneously collected data was used. This design allows for the transformation of one type of result to another (e.g. themes into counts).<sup>23</sup> Quantitative data consisted of DOW and qualitative data of recorded telephone consultations. Deductive thematic analysis of the qualitative data was conducted and used to explore the content of the quantitatively scaled DOW, using the framework of the CSM theory.

#### Setting

The OOH services and the Emergency Medical Services, Copenhagen, the Capital Region of Denmark, are integrated in one organisation and can be reached through two telephone numbers; 112 for life-threatening emergencies and 1813 for acute, non-emergent medical calls. The Medical Helpline 1813 is available from 4pm to 8am on weekdays and around the clock on weekends and holidays. Individuals may also call 1813 for a referral to an emergency department, if they cannot get in touch with their general practice (GP) during regular working hours. All access to acute care is pre-assessed by telephone triage. Annually, approximately one million calls are handled by call handlers (nurses/physicians) who triage the caller to self-care, a general practitioner, face-to-face assessment/consultation at a hospital, home visit or direct hospitalisation.<sup>24 25</sup>

#### **Data collection**

A total of 261 callers to the OOH services, The Medical Helpline 1813, during a three-day time period were approached for inclusion in this study. As a new rating scale was being implemented by the call handlers, it was considered, that this was a reasonable length of time. All calls from adults ( $\geq$ 15 years of age) concerning somatic illness were deemed eligible for inclusion. Calls made on behalf of another person, including children (n=16) were excluded, in order to have a study population exclusively describing personal symptoms. Furthermore, calls in which consent was not granted (n=1), calls in which the call handler failed to ask study questions (n=19), calls in which there were technical problems with the call recording (n=33) and repeat callers (n=12) were also excluded. This resulted in a convenience sample of a total of 180 calls. Data were collected for three consecutive days: Wednesday 20<sup>th</sup> April and Thursday 21<sup>st</sup> April (4pm to 10pm) and Friday 22<sup>nd</sup> April (8am to 4pm) 2016 (a bank holiday), 2016. The study was approved by the Data Protection Agency, Denmark.

#### Data sources

Data consisted of two parallel strands – the quantitative scaled DOW and illness representation presented by the callers – both derived from the recorded telephone consultations. Two experienced call handlers were first asked to assess and recommend question phrasing for data collection. All call handlers participated in data collection and received instructions on procedure, inclusion criteria, study focus and voluntary caller participation. Based on the recommendations, call handlers were instructed to ask the following questions in each call: "What is your reason for calling in today?", "How long have you been experiencing these symptoms?" and "On a scale from 1-10, how worried are you?". Additional questions were asked at the call handlers' discretion as they deemed relevant and the caller was invited to participate in the study, giving verbal informed consent. Data were collected throughout the course of the consultation. Calls in which the caller failed to provide a number reflecting their DOW (n=10), were assessed by two researchers and using the intensity verbal descriptors (see table 1, Duncan *et al*<sup>26</sup>) assigned a numeric value (1 to 10). If not concurrent, a consensus was reached through discussion. The intensity verbal descriptors used, describe the intensity of pain and not worry. However, as both pain and worry are subjective, it was felt, that in these few cases, the intensity descriptors for pain were an adequate tool.

#### Patient and public involvement

The development of the research aim, design, recruitment, conduct and outcome measures in this study were not based on patients' involvement. The results of this study will not automatically be disseminated to study participants. However, participants can request information regarding this study.

#### ANALYSIS

The recorded telephone consultations were transcribed in NVivo V.11 and DOW were attached to each call as attributes. According to the information given by the callers, symptom duration (timeline) was categorised into three groups: less than 5 hours, 5 to 24 hours and more than 24 hours. The remaining qualitative data were deductively coded according to the last four components of the CSM framework, by the main author. For the purpose of simplicity, the results were then sub-grouped into: low DOW (DOW 1 to 4), moderate DOW (DOW 5 and 6) and high DOW (DOW 7 to 10). Furthermore, the results were compared to two previous studies: Farquharson *et al*<sup>21</sup> and Lau *et al*.<sup>27</sup>

#### Qualitative data analysis

The qualitative data were created by coding the transcripts deductively according to the four components of the CSM framework (identity, cause, cure/control and consequence), while disregarding the DOW value. For each of the four components, data were clustered and patterns identified. Three themes within each component were derived from these patterns and each theme was recoded, as described by Braun and Clarke.<sup>28</sup> The patterns and thereby derived theme definitions, were discussed and agreed upon with a second researcher, using 50% of the study

data. The remaining data were rechecked and recoded if necessary, by the main researcher, according to the agreed theme definitions.

#### Mixed methods analysis

All 180 calls were grouped according to themes in each of the five CSM components and listed according to DOW (1-10). For each theme, the quantiles (Q1-Q3) and median were calculated and a box and whisker plot created.

#### RESULTS

#### Participants

A total of 261 callers to the OOH services during the three-day time period were approached for inclusion. Of these, 81 callers were excluded, based on the exclusion criteria, leaving a total of 180 callers to be included in this study. Due to this limited size of the study population, there is a lack of statistical power. The nature of the calls was as follows: acute illness (n = 120), injury (n = 37), exacerbation of chronic disease (n = 15), other (n = 7), and undetermined (n = 1), which is representative for calls to the OOH services.<sup>29</sup> (See table 1.)

| DOW                 | Low DOW<br>(1-4)      | Moderate DOW<br>(5-6) | High DOW<br>(7-10) |
|---------------------|-----------------------|-----------------------|--------------------|
| Total study callers | 76                    | 39                    | 65                 |
| Women               | 43 (57%) <sup>i</sup> | 24 (62%)              | 47 (72%)           |
| Men                 | 33 (43%)              | 15 (38%)              | 18 (28%)           |
| Age 15-20 years     | 4 (5%)                | 5 (13%)               | 10 (15%)           |
| Age 21-40 years     | 46 (61%)              | 19 (49%)              | 26 (40%)           |
| Age 41-65 years     | 19 (25%)              | 13 (33%)              | 21 (32%)           |
| Age >65 years       | 7 (9%)                | 2 (5%)                | 8 (12%)            |

#### Table 1. Participant demographics

<sup>i</sup>Percentages of total callers in each DOW group.

#### Quantitative findings according to the CSM framework

All callers referred to identity, as well as duration (timeline) of their symptoms. Callers with a low DOW were more likely to mention a cause for their illness (82%) than other callers, whereas, reference to cure/control was similar (78%, 79% and 74%) in all three DOW sub-groups. Callers in all three DOW sub-groups were least likely to refer to consequence compared to the other four CSM components; however, callers with a high DOW were more likely to refer to a consequence (48%) of their illness than callers with moderate (28%) or low DOW (33%). (See figure 1.)

#### (Placement of figure 1.)

#### Qualitative findings

#### Identity

Callers' referrals to the identity of their perceived health threat were divided into three themes: Strong identity; use of a definitive label or diagnosis, reference to a previous identical experience, reference to a known condition and/or expression of certainty (n=56), *medium identity*; hypothesis of label or diagnosis, reference to a previous similar, but not identical experience and/or expression of near certainty (n=90) and *weak identity*; no mention of label or diagnosis, no reference to a previous experience, reference to an unknown condition and/or expression of uncertainty (n=34).

#### Timeline

Fifty-two callers described symptoms which had lasted *less than 5 hours*, 44 callers described symptoms which had lasted *between 5 and 24 hours* and 84 callers described symptoms which had lasted *more than 24 hours*.

#### Cause

A possible cause of symptoms or illness was reported by 132 callers (73%). The reported causes were divided into the following three themes: *clear cause*; expression of certainty (n=90); *unclear cause*; a hypothesis suggested or expression of uncertainty (n=42); and *no mention of cause* (n=48).

#### Cure/control

Reference pertaining to a cure or control related to their symptoms or illness was made by 138 callers (77%). These were divided in to the following three themes: *clear solution for cure/control*; specific request for treatment (n=42), *unclear solution for cure/control*; suggestion for treatment or had attempted self-treatment with little or no effect (n=96), and *no mention of cure/control* (n=42).

#### Consequence

Reference to a consequence of their symptoms or illness was made by 67 callers (37%). These were categorized into the following three themes: *high consequence*; potentially long-term or life-threatening consequences and consequences severely affecting work or social life (n=36), *low consequence;* short-term consequences, consequences affecting immediate daily life or mildly affecting work or social life (n=31) and *no mention of consequence* (n=113).

(See table 2 for examples of citations of each theme. Citations were chosen to represent the breadth of definition of each theme.)

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| Identity | Themes                        | Examples of citations                                 |
|----------|-------------------------------|---|
| n=180    |                               |   |
| (100%)   | Strong identity               | "I have a bladder infection I have to peo all the     |
|          | n=56 (31%)                    | timeI also had a UTI last summer"                     |
|          |                               | "I rubbed my eye and now it is red and there is       |
|          |                               | pus it is an eye infectionI know it goes away,        |
|          |                               | as I have had it before"                              |
|          |                               | "My right big toe is swollen, the area next to the    |
|          |                               | nail is red and infected, I can press pus out"        |
|          | Medium                        | "I have had genital herpes many times before, but     |
|          | <b>identity</b><br>n=90 (50%) | it looks differentmaybe it is just a yeast infection" |
|          |                               | "sudden pain after I sneezedI think I might           |
|          |                               | have punctured a lung or bruised a rib"               |
|          |                               | "I have a favor and my throat hurta I think I'm       |
|          |                               | sick it's usually a throat infection "                |
|          | Weak identity                 | "I suddenly got a severe pain in the left, lower side |
|          | n=34 (19%)                    | of my abdomenI have never tried anything like it      |
|          |                               | beforeI cannot figure out why I am in so much         |
|          |                               | pain"   |
|          |                               | "I have had two attacks of chest pain and cold        |
|          |                               | sweatsI do not usually feel like thisdoes not         |
|          |                               | feel like pain that I have tried beforeI just want to |
|          |                               | know why"   |
|          |                               | "I feel really bad; have had a fever for 3-4 days and |
|          |                               | I'm coughing a lot. Yesterday, I had the shakes and   |
|          |                               | I threw up"   |
| Timeline | <5 hours                      | "I just fell and cut my forehead and it is            |
| n=180    | n=52 (29%)                    | bleeding"   |
| (100%)   | 5-24 hours                    | "I started feeling sick this morning, but I still     |
|          | n=44 (24%)                    | decided to go to work"                                |
|          | >24 hours                     | "it's been going on for a few days now"               |
|          | n=84 (47%)                    |   |
| Cause    | Themes                        | Examples of citations                                 |
| n=132    |                               |   |
| (73%)    |                               |   |
|          |                               | shoulder  |
|          | 11-30 (30%)                   |   |

|   | "When I feel like this, it is usually tonsillitis"  |
|---|---|
|   | "After skatingpain in my leg muscle strain seems very logical"  |
| Unclear cause<br>n=42 (23%)                   | "I think it could be a mixture of stress and bacteria"  |
|   | "It is not an allergymy immune system might be a bit affected because I have been travelling a lot"   |
| O.  | "It looks like hives, but I do not have any allergies"  |
| <b>No cause</b><br>n=48 (27%)                 |   |
| Themes  | Examples of citations   |
|   | C   |
| Clear solution                                | "I want to go to the hospital and get stitches"   |
| for cure/control                              | "I have triad it before when I get perioillin I am  |
| 11=42 (23%)                                   | going to try to convince you to give it me again"   |
|   | "I have spoken to my husband, who is a doctor,<br>and he believes I need to be seen by an eye<br>specialist"  |
| Unclear<br>solution for                       | "I have gotten painkillers from the dentist, but they<br>are not helping; can I take Panodil as well?"  |
| n=96 (53%)                                    | "I tried getting in contact with my GP, but no one is picking up the phone"   |
|   | "Do I have to do anything about it tonight or can it wait until I call my GP tomorrow?"   |
| No solution for<br>cure/control<br>n=42 (23%) |   |
| Themes  | Examples of citations   |
|   |   |
|   | Unclear cause<br>n=42 (23%)<br>No cause<br>n=48 (27%)<br>Themes<br>Clear solution<br>for cure/control<br>n=42 (23%)<br>Unclear<br>solution for<br>cure/control<br>n=96 (53%)<br>No solution for<br>cure/control<br>n=42 (23%) |

|                                  | "I am pregnant, can it affect the baby?"              |
|----------------------------------|---|
|                                  | "I read on Google, that it could be cancer"           |
| Low<br>consequence<br>n=31 (17%) | "I cannot sleep or eat anything, because of the pain" |
|                                  | "Maybe I cannot go out riding tomorrow"               |
|                                  | "I have to travel for work tomorrow"                  |
| No<br>consequence<br>n=113 (63%) |   |

#### Table 2. Thematic analysis of the components of the CSM framework

#### Mixed methods findings

A clear trend was observed. Study callers with a medium identity seemed to have a higher DOW, whereas, callers with a strong identity seemed to have a lower DOW and callers with a weak identity generally seemed to have a moderate DOW. There were more callers with a low DOW who had an illness lasting less than 24 hours than callers who had an illness lasting more than 24 hours. Callers with a clear cause for their illness and a clear solution for cure/control seemed to have a low DOW and finally, callers who mentioned a high consequence to their illness seemed to have a high DOW. (See figure 2.) Lich

#### (Placement of figure 2.)

#### DISCUSSION

#### Summary of main findings

Using the five components of the CSM framework, as described by Leventhal<sup>18</sup>, our analysis demonstrated that callers presenting their illness to OOH services to a large extent referred to all five components, regardless of their self-evaluated DOW. All callers referred to identity and timeline and callers were least likely to refer to consequence.

Lower DOW seemed to be more present in the group of callers who had a strong illness identity, illness duration of less than 24 hours, a clear cause and a clear solution. Callers who presented a medium or weak illness identity, illness duration of more than 24 hours, an unclear or no cause, unclear or no solution and a perception of high consequence seemed to present a higher DOW.

#### Strengths and limitations of this study

The main strength of this study was the use of mixed methods approach, which gave an in-depth insight and enabled a thorough analysis and understanding of the illness representation of patients to an OOH service. In addition, patients' illness representation and reported self-evaluation of DOW were obtained in real time, as the callers were seeking help. Findings were, therefore, not

influenced by recall bias. DOW was not uniformly obtained at a specific time within the consultation. Therefore, the consultation itself could influence the patient's DOW and the patient's DOW could influence the consultation. This, however, is representative of real-life calls to OOH services and how DOW can be used as a potential triage tool. Use of the NVivo V.11 software and researcher triangulation ensure that the coding of the data is available for independent analysis and less subject to personal bias. Due to the short duration of data collection, the size of the study population was limited, resulting in a lack of statistical power. However, irrespective of this limitation, the analyses of the results, using the mixed methods approach, show a distinct trend and relation between DOW as a measure of patient-evaluated urgency and their illness representation.

#### Comparison with existing literature

The results of the quantitative data can be compared to work done by Farquharson *et al*<sup>21</sup> and Lau *et al.*<sup>27</sup> (See table 3.) Participants in both studies and in all three DOW sub-groups in the present study mentioned factors pertaining to all five components of the CSM framework. Farquharson *et al*, however, solely based their data on information that callers volunteered, without call handler prompting, but suggested that it may be necessary for call handlers to prompt remaining components to obtain a comprehensive understanding of patients' representations of illness. In this study, all information from the caller was coded, including information prompted by the call handler, thus the prevalence in each of the five CSM components was greater compared to those found by Farquharson et al. The method used in this study provides a more complete portrayal of the caller's illness representation and is more representative of real-life calls to OOH services.

|              |                    | Present study           |                     | Previous stu   | ıdies   |
|--------------|--------------------|-------------------------|---------------------|--|---|
|              | Low<br>DOW<br>N=76 | Moderate<br>DOW<br>N=39 | High<br>DOW<br>N=65 | Farquharson <i>et al</i> <sup>(21)</sup><br>(2011)<br>N=59 | Lau <i>et al</i> <sup>(27)</sup><br>(1989)<br>N=887 |
| Identity     | 100                | 100                     | 100                 | 100  | 96  |
| Timeline     | 100                | 100                     | 100                 | 44   | 49  |
| Cause        | 82                 | 72                      | 65                  | 15   | 28  |
| Cure/control | 78                 | 79                      | 74                  | 37   | 32  |
| Consequence  | 33                 | 28                      | 48                  | 14   | 33  |

## Table 3. Prevalence (%) of components of illness representation

#### Relevance of this study: possible implications for health care providers and policy makers

This study suggests a relation between patients' illness representation, as presented telephonically to an OOH services call handler, and their self-evaluation of urgency, defined as DOW. The relation observed, is that DOW is not random, but follows a pattern, depending on patients' illness representation. This pattern can aid call handlers in understanding patients' perception of urgency, potentially aiding the triage process.

This is a new area of research and this study gives direction for future research to further strengthen the evidence. Research on coherence between patient DOW and call handlers', ED

and GP physicians' assessment of urgency, both prospectively and retrospectively will strengthen the basis for potential use of DOW as a triage tool. Incorporating DOW as an additional tool in the telephone triage process could potentially aid in the determination of urgency and the type of health care needed, thus increasing patient safety.

#### Figure legends

Figure 1. Prevalence (%) of components of illness representation in present study

Figure 2. Relation between DOW and the components of the CSM framework

#### Footnotes

**Contributorship statement:** SLT and HGJ planned the study and discussed and agreed upon theme definitions in the qualitative analysis. HGJ planned and performed the data collection. SLT extracted and analysed the data and drafted the manuscript. IE and FKL supervised and contributed substantially to the critical revision. All authors read and approved the final manuscript.

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**Data sharing statement:** Additional data that are not available online can be obtained by contacting the corresponding author.

**Ethical statement:** The study was approved by the Data Protection Agency (PVH-2015-004, I-Suite nr.: 04330). All participants gave informed consent. The Ethical Committee was consulted but no permission was needed (H-15016323).

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Figure 1. Prevalence (%) of components of illness representation in present study

61x21mm (300 x 300 DPI)

None



BMJ Open

#### STROBE (Strengthening The Reporting of OBservational Studies in Epidemiology) Checklist

A checklist of items that should be included in reports of observational studies. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

**Note:** An Explanation and Elaboration article discusses each checklist item and gives methodological background and published examples of transparent reporting. The STROBE checklist is best used in conjunction with this article (freely available on the Web sites of PLoS Medicine at <a href="http://www.plosmedicine.org/">http://www.plosmedicine.org/</a>, Annals of Internal Medicine at <a href="http://www.annals.org/">http://www.annals.org/</a>, and Epidemiology at <a href="http://www.epidem.com/">http://www.annals.org/</a>, and Epidemiology at <a href="http://www.strobe-statement.org">http://www.strobe-statement.org</a>.

| Section and item     | ltem<br>No. | Recommendation  | Reported or<br>Page No. |
|----------------------|-------------|---|-------------------------|
| Title and Abstract   | 1           | (a) Indicate the study's design with a commonly used term in the title or the   |                         |
|                      |             | abstract  |                         |
|                      |             | (b) Provide in the abstract an informative and balanced summary of what was   |                         |
|                      |             | done and what was found   |                         |
| Introduction         |             |   |                         |
| Background/Rationale | 2           | Explain the scientific background and rationale for the investigation being   |                         |
|                      |             | reported  |                         |
| Objectives           | 3           | State specific objectives, including any prespecified hypotheses  |                         |
| Methods              |             |   |                         |
| Study Design         | 4           | Present key elements of study design early in the paper   |                         |
| Setting              | 5           | Describe the setting, locations, and relevant dates, including periods of   |                         |
| _                    |             | recruitment, exposure, follow-up, and data collection   |                         |
| Participants         | 6           | (a) Cohort study—Give the eligibility criteria, and the sources and methods of  |                         |
|                      |             | selection of participants. Describe methods of follow-up  |                         |
|                      |             | Case-control study—Give the eligibility criteria, and the sources and methods of                                      |                         |
|                      |             | case ascertainment and control selection. Give the rationale for the choice of  |                         |
|                      |             | cases and controls  |                         |
|                      |             | <i>Cross-sectional study</i> —Give the eligibility criteria, and the sources and methods of selection of participants |                         |
|                      |             | (b) Cohort study—For matched studies, give matching criteria and number of  |                         |
|                      |             | exposed and unexposed   |                         |
|                      |             | <i>Case-control study</i> —For matched studies, give matching criteria and the number                                 |                         |
|                      |             | of controls per case  |                         |
| Variables            | 7           | Clearly define all outcomes, exposures, predictors, potential confounders, and  |                         |
|                      |             | effect modifiers. Give diagnostic criteria, if applicable   |                         |

| Section and Item       | ltem<br>No. | Recommendation   | Reporte<br>Page I |
|------------------------|-------------|--|-------------------|
| Data Sources/          | 8*          | For each variable of interest, give sources of data and details of methods of              |                   |
| Measurement            |             | assessment (measurement). Describe comparability of assessment methods if                  |                   |
|                        |             | there is more than one group   |                   |
| Bias                   | 9           | Describe any efforts to address potential sources of bias                                  |                   |
| Study Size             | 10          | Explain how the study size was arrived at  |                   |
| Quantitative Variables | 11          | Explain how quantitative variables were handled in the analyses. If applicable,            |                   |
|                        |             | describe which groupings were chosen and why   |                   |
| Statistical Methods    | 12          | (a) Describe all statistical methods, including those used to control for                  |                   |
|                        |             | confounding  |                   |
|                        |             | (b) Describe any methods used to examine subgroups and interactions                        |                   |
|                        |             | (c) Explain how missing data were addressed  |                   |
|                        |             | (d) Cohort study—If applicable, explain how loss to follow-up was addressed                |                   |
|                        |             | <i>Case-control study</i> —If applicable, explain how matching of cases and controls was   |                   |
|                        |             | addressed  |                   |
|                        |             | <i>Cross-sectional study</i> —If applicable, describe analytical methods taking account of |                   |
|                        |             | sampling strategy  |                   |
|                        |             | (e) Describe any sensitivity analyses  |                   |
| Results                |             |  | 1                 |
| Participants           | 13*         | (a) Report numbers of individuals at each stage of study—eg numbers potentially            |                   |
|                        |             | eligible, examined for eligibility, confirmed eligible, included in the study,             |                   |
|                        |             | completing follow-up, and analysed   |                   |
|                        |             | (b) Give reasons for non-participation at each stage                                       |                   |
|                        |             | (c) Consider use of a flow diagram   |                   |
| Descriptive Data       | 14*         | (a) Give characteristics of study participants (eg demographic, clinical, social) and      |                   |
|                        |             | information on exposures and potential confounders   |                   |
|                        |             | (b) Indicate number of participants with missing data for each variable of interest        |                   |
|                        |             | (c) Cohort study—Summarise follow-up time (eg, average and total amount)                   |                   |
| Outcome Data           | 15*         | Cohort study—Report numbers of outcome events or summary measures over                     |                   |
|                        |             | time   |                   |
|                        |             | <i>Case-control study</i> —Report numbers in each exposure category, or summary            |                   |
|                        |             | measures of exposure   |                   |
|                        |             | Cross-sectional study—Report numbers of outcome events or summary measures                 |                   |
|                        |             |  |                   |

| 1<br>2         | Section and Item             | ltem<br>No. | Recommendation  | Reported on<br>Page No. |
|----------------|------------------------------|-------------|---|-------------------------|
| 3              | Main Results                 | 16          | (a) Give unadjusted estimates and, if applicable, confounder-adjusted estimates           |                         |
| 4              |                              |             | and their precision (eg, 95% confidence interval). Make clear which confounders           |                         |
| 5<br>6         |                              |             | were adjusted for and why they were included  |                         |
| 7<br>8         |                              |             | (b) Report category boundaries when continuous variables were categorized                 |                         |
| 9              |                              |             | (c) If relevant, consider translating estimates of relative risk into absolute risk for a |                         |
| 10<br>11       |                              |             | meaningful time period  |                         |
| 12<br>13       | Other Analyses               | 17          | Report other analyses done—eg analyses of subgroups and interactions, and                 |                         |
| 14             |                              |             | sensitivity analyses  |                         |
| 15<br>16<br>17 | Discussion                   |             |   |                         |
| 18<br>19       | Key Results                  | 18          | Summarise key results with reference to study objectives                                  |                         |
| 20             | Limitations                  | 19          | Discuss limitations of the study, taking into account sources of potential bias or        |                         |
| 21<br>22       |                              |             | imprecision. Discuss both direction and magnitude of any potential bias                   |                         |
| 23             | Interpretation               | 20          | Give a cautious overall interpretation of results considering objectives, limitations,    |                         |
| 24<br>25       |                              |             | multiplicity of analyses, results from similar studies, and other relevant evidence       |                         |
| 26<br>27       | Generalisability             | 21          | Discuss the generalisability (external validity) of the study results                     |                         |
| 28<br>29       | Other Information            |             | R.  |                         |
| 30<br>21       | Funding                      | 22          | Give the source of funding and the role of the funders for the present study and, if      |                         |
| 32             |                              |             | applicable, for the original study on which the present article is based                  |                         |
| 33<br>34       |                              |             |   |                         |
| 35             | *Give information separation | ately for   | cases and controls in case-control studies and, if applicable, for exposed and unexpose   | ed groups in            |
| 36<br>37       | cohort and cross-section     | al studie   | is.   |                         |
| 38<br>30       | Once you have complete       | ed this c   | hecklist, please save a copy and upload it as part of your submission. DO NOT include     | e this                  |
| 40             | checklist as part of the n   | nain ma     | nuscript document. It must be uploaded as a separate file.                                |                         |
| 41             |                              |             |   |                         |
| 42<br>43       |                              |             |   |                         |

#### COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

| Торіс                                   | Item No. | Guide Questions/Description  | Reported o |
|---|----------|--|------------|
| Domain 1: Possarch toam                 |          |  | Page No.   |
| and reflexivity                         |          |  |            |
| Personal characteristics                |          |  |            |
| Interviewer/facilitator                 | 1        | Which author/s conducted the interview or focus group?                   |            |
| Credentials                             | 2        | What were the researcher's credentials? E.g. PhD, MD                     |            |
| Occupation                              | 3        | What was their occupation at the time of the study?                      |            |
| Gender                                  | 4        | Was the researcher male or female?                                       |            |
| Experience and training                 | 5        | What experience or training did the researcher have?                     |            |
| Relationship with                       |          | ~  |            |
| participants                            |          | <u> </u>   | -          |
| Relationship established                | 6        | Was a relationship established prior to study commencement?              |            |
| Participant knowledge of                | 7        | What did the participants know about the researcher? e.g. personal       |            |
| the interviewer                         |          | goals, reasons for doing the research                                    |            |
| Interviewer characteristics             | 8        | What characteristics were reported about the inter viewer/facilitator?   |            |
|   |          | e.g. Bias, assumptions, reasons and interests in the research topic      |            |
| Domain 2: Study design                  |          |  |            |
| Theoretical framework                   |          |  |            |
| Methodological orientation              | 9        | What methodological orientation was stated to underpin the study? e.g.   |            |
| and Theory                              |          | grounded theory, discourse analysis, ethnography, phenomenology,         |            |
|   |          | content analysis   |            |
| Participant selection                   |          |  |            |
| Sampling                                | 10       | How were participants selected? e.g. purposive, convenience,             |            |
|   |          | consecutive, snowball  |            |
| Method of approach                      | 11       | How were participants approached? e.g. face-to-face, telephone, mail,    |            |
| Sampla siza                             | 12       | How many participants were in the study?                                 |            |
| Non participation                       | 12       | How many participants were in the study!                                 |            |
| Cotting                                 | 15       | How many people refused to participate or dropped out? Reasons?          |            |
| Setting of data collection              | 1.4      | Where we the data collected 2 c. c. home, clinic, workplace              |            |
|   | 14       | where was the data collected? e.g. nome, clinic, workplace               |            |
| Presence of non-                        | 15       | was anyone else present besides the participants and researchers?        |            |
| participants<br>Description of severals | 10       |  |            |
| Description of sample                   | 16       | what are the important characteristics of the sample? e.g. demographic   |            |
| Data collection                         |          | data, date   |            |
|   | 47       |  |            |
| Interview guide                         | 1/       | Were questions, prompts, guides provided by the authors? Was it pilot    |            |
| <b>5</b>                                | - 10     | tested?  |            |
| kepeat interviews                       | 18       | were repeat inter views carried out? If yes, how many?                   |            |
| Audio/visual recording                  | 19       | Did the research use audio or visual recording to collect the data?      |            |
| Field notes                             | 20       | Were field notes made during and/or after the inter view or focus group? |            |
| Duration                                | 21       | What was the duration of the inter views or focus group?                 |            |
| Data saturation                         | 22       | Was data saturation discussed?   |            |
| Transcripts returned                    | 23       | Were transcripts returned to participants for comment and/or             |            |

|   | Торіс                        | Item No. | Guide Questions/Description  | Reported on<br>Page No. |
|---|------------------------------|----------|--|-------------------------|
|   |                              |          | correction?  |                         |
|   | Domain 3: analysis and       |          |  |                         |
|   | findings                     |          |  |                         |
|   | Data analysis                |          |  |                         |
|   | Number of data coders        | 24       | How many data coders coded the data?                                     |                         |
|   | Description of the coding    | 25       | Did authors provide a description of the coding tree?                    |                         |
|   | tree                         |          |  |                         |
|   | Derivation of themes         | 26       | Were themes identified in advance or derived from the data?              |                         |
|   | Software                     | 27       | What software, if applicable, was used to manage the data?               |                         |
|   | Participant checking         | 28       | Did participants provide feedback on the findings?                       |                         |
|   | Reporting                    |          |  |                         |
| ľ | Quotations presented         | 29       | Were participant quotations presented to illustrate the themes/findings? |                         |
|   |                              |          | Was each quotation identified? e.g. participant number                   |                         |
|   | Data and findings consistent | 30       | Was there consistency between the data presented and the findings?       |                         |
|   | Clarity of major themes      | 31       | Were major themes clearly presented in the findings?                     |                         |
|   | Clarity of minor themes      | 32       | Is there a description of diverse cases or discussion of minor themes?   |                         |

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. International Journal for Quality in Health Care. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.