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“Just like a normal pain”- experiences of myocardial infarction among people with diabetes mellitus - a qualitative study.

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8 **“Just like a normal pain”- experiences of myocardial**
9 **infarction among people with diabetes mellitus - a**
10 **qualitative study.**
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Abstract

Objective: The objective of the study was to investigate the symptoms people with diabetes experience when having a myocardial infarction, their illness narrative, and how they present to health services.

Setting: Secondary care -3 London (UK) hospitals- Coronary care units (CCU) and medical wards.

Participants: Patients were recruited from CCU with diabetes (Type 1 & 2) with a clinical presentation of MI (STEMI, NSTEMI, acute MI unspecified and cardiac arrest). 43 participants were recruited, 39 interviews meeting the detailed study criteria were used in the analysis. They were predominantly male (n=30), aged 40-90 years and white British (18/39), just under a half were from other ethnic groups. The majority had type II DM (n=35); 24 had had a non ST elevated myocardial infarction (NSTEMI), 10 had a ST elevated myocardial infarction (STEMI) and 5 had other cardiac events (Acute MI unspecified).

Definitions of selection and exclusion criteria: Eligibility criteria included a diagnosis of MI (AHA criteria), and DM, the ability to communicate enough English to complete the interview. Ward staff made a clinical judgement (ethics requirement) that the participant was post-treatment, clinically stable and well enough to participate.

Results: While most participants did experience chest pain, it was often not their most striking symptom. As their chest pain did not match their expectations of what a “heart attack” should be, participants developed narratives to explain these symptoms, including the symptoms being effects of their DM (“hypos”), side effects of medication (oral hypoglycaemics) or symptoms (such as breathlessness and indigestion) related to other comorbidities; often leading to a delay in seeking care.

Conclusions:

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While truly absent chest pain during MI among people with DM was rare in this study, patients' attenuated symptoms often led to delay in seeking attention, diagnostic confusion and delayed treatment from doctors.

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3 **Data sharing:** - No additional data available.
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6 **Article summary**
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8 Strengths and weaknesses
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11 This is a study of people with diabetes experiencing an MI

12 Strengths of the study include:

- 13
14 • contemporaneous patients' descriptions of their symptoms and illness
15 narrative just after an MI,
16
17 • a model of how attenuated MI symptoms might alter help seeking behaviour,
18
19 • the participants were from a wide demographic background in terms of age,
20 ethnicity and disease burden.
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24 Weaknesses include
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- 26 • that by recruiting patients from CCU means we will not have captured
27 markedly discrepant presentations,
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29 • by recruiting on the basis of the ability to communicate in English means we
30 will have lost some cultural and linguistic nuance in symptom presentation.
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Background

Diabetes Mellitus (DM) is a common health problem worldwide and affects 4-6% of the UK population.¹ Cardiovascular disease (CVD) is the major life threatening complication of DM in the UK.^{2 3 4} Myocardial infarction (MI) is the principal cause of excess mortality among those with DM, with a 3-fold increased risk of coronary heart disease (CHD) mortality,^{5 6} a 6-fold increased risk of myocardial infarction (MI)⁷ and a worse prognosis from MI compared with non-diabetic populations.⁸

Possible mechanisms of this excess mortality risk include comorbidities such as hypertension, dyslipidaemia and chronic kidney disease. An important element in this observed increased mortality may be late or missed presentation by patients, and diagnosis by clinicians.

Up to a third of people who suffer an MI can have no chest pain; however people with DM make up a larger proportion of this group (32.6% vs 25.4% in one study).⁹ However, when people with DM do have symptoms of an MI, their symptoms may often be atypical¹⁰ or unusual.¹¹

Nevertheless, there is conflicting evidence around this issue: Funk found no statistically significant difference in CHD symptom presentation in people with and without DM, but did report non-significant increases in dyspnoea, neck and throat pain among those with DM.¹² Kentsch found no differences between these groups in the frequency or severity of chest pain but also identified differences in the prevalence of dyspnoea.¹³ One review found conflicting results about MI symptoms among women with and without DM.¹⁴

There are several methodological reasons why these studies may have conflicting results: being underpowered,^{15 16} being unrepresentative of the population at risk¹⁵, or recruited from highly selected hospital populations.¹⁷ Survivor bias (i.e. living to tell the tale of your symptoms) may also be an important issue in a condition such as MI which has a high early mortality.

Clinician classification

The way clinicians ask about chest symptoms may also be problematic. Clinicians ask about “chest pain”, however the term “pain”,^{18 19} is often not used by patients experiencing MI.

There is a biological basis for altered perception of pain among diabetics in that cardiac autonomic neuropathy (CAN) is a complication of DM and leads to altered pain perception, meaning a patient might not experience pain caused by myocardial ischaemia.²⁰

In the current study, we aimed to address some of the limitations of previous research by recruiting only DM patients with clear evidence of a recent MI, regardless of their chest pain presentation, and use of a qualitative methodology to explore how these patients describe their symptoms. Qualitative methods can help overcome a narrow clinician focus and help develop a patient orientated view when exploring symptoms of disease.^{21 22 23}

Methods

This was a qualitative study where interviews were undertaken with patients with DM who have recently had a confirmed MI, recruited within coronary care units (CCU). Eligibility criteria included a confirmed diagnosis of MI (according to AHA criteria ²⁴), a clinical diagnosis of DM and the ability to communicate (understand and speak) enough English to complete the interview. Clinical staff ensured the participant was post-treatment, clinically stable and well enough to participate. This subjective judgement was made by the clinical staff involved in participants' care as required by the ethics committee. Participants were approached as soon as possible after the diagnosis so we could be sure that they had had an MI (usually a retrospective or working diagnosis) and to minimise recall bias about symptoms. Once invited, they were given 24 hours to decide whether to participate (see comments regarding ethics approval). The interviews took place in three London, UK hospitals. We aimed to recruit consecutive patients (but this proved unworkable) so this was a pragmatic sample.

The interviews were semi-structured, iterative interviews building from a topic guide based on Funk's acute myocardial infarction (AMI) symptom list ¹² to include a narrative of the course, range, character and severity of the symptoms the person experienced before and during their MI. A checklist of AMI symptoms was worked through to ensure symptoms were absent and not just omitted. Ideas about expected symptoms of an MI, and symptom attribution were also explored as people often develop complex narratives about their illnesses. ²⁵ We also explored participants' thoughts about their illness, treatments they had attempted, motives and triggers for seeking help, awareness and knowledge of the symptoms of a heart attack.

Interviews were audio recorded, field notes and baseline patient information were noted. Details gathered included the type of MI (ECG changes, troponin level, clinical assessment), the patients' demographics, co-morbidities (type and duration of DM, other disease), risk factors, family history, medication use and information that might impact on symptom perception, from the informant and their medical records. All participants were allocated a code number to link their data together and then

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3 anonymised (apart from the consent form) so that identifiable data did not leave the
4 ward setting.
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7 The audio taped interviews were transcribed verbatim and manually analysed using
8 the thematic framework.²⁶ Two independent researchers (NT, DDC) read the
9 transcripts and analysed the data using the following steps: familiarisation,
10 identifying a thematic framework, indexing, charting, mapping and interpretation.
11 Throughout this process, transcripts were repeatedly re-read to focus on specific
12 points and ideas, to verify the presence of the themes that are identified and ensure
13 the context of the themes has been preserved. Disagreements were resolved by
14 discussion with a third team member (MJ). Agreement was specifically sought
15 between reviewers about the classification of symptoms as either typical or atypical
16 as outlined by Funk.¹² This is distinct to Diamond and Forrester's classification of
17 angina typicality.²⁷ Representative quotes (with consent) were used and have
18 identifying details to link the theme to the interview transcript.
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28 The lay term "heart attack" is used extensively in the transcripts, this can have a
29 broad popular meaning but we will assume is used by participants to suggest a
30 myocardial infarction.
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34 Ethical approval for this study and the use of quotes was obtained from the
35 Hertfordshire Research Ethics Committee. (Project no: 11/EE/0045). The committee
36 requested that we allowed a "cool off" period of 24 hours from approach to obtaining
37 consent. Data protection and local hospital trust R&D policies were followed.
38 Consent was not originally sought to disclose the full interview transcripts.
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43 Patient involvement

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45 The original idea for this study was based on a clinical encounter in general practice.
46 A patient consulted MJ his GP, having suffered a severe MI despite having minimal
47 symptoms and subsequently developed severe heart failure. Before his death, this
48 patient agreed to support research in this area and filmed a brief video of his
49 experiences. A broader study (with same research question but a different
50 methodology) on this field was presented and supported by the North East London
51 Diabetes Research Network Lay Panel Meeting in 2011. Patients' narratives
52 constitute the data underlying this study.
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Results

Forty three participants were recruited from the participating hospitals, however 4 interviews proved unusable due to not meeting study recruitment criteria on detailed case review and were excluded resulting in a total of 39 participants. The interviews had a mean duration of 20mins 33 sec (with a range of 5 mins 14 secs to 48mins 46 secs) and were all undertaken by one interviewer; NB. The study comprised of 30 men and 9 women; with an age range of 40-90, 35 participants had type 2 DM and 4 had type 1 DM. All participants had confirmed acute coronary syndrome; 24 had NSTEMIs, 10 had STEMIs and 5 had other MIs (acute MI-unspecified including 4 cardiac arrests). Their ethnic categories were White British (n=18), Asian/ south Asian (n=7), African or Afro-Caribbean (n=3) and others (n=5) e.g. Turkish, Maltese etc. A number (n=6) declined to state their ethnicity or instead identified their religious affiliation e.g. "Church of England", "Jewish" etc. One interview was done via an informal family translator but frequently family members would participate in the interview, clarifying the order of events or reminding the participant about elements of their illness narrative (which may have been clouded by their illness including cardiac arrest or treatment such as strong opioid analgesics). Participants were usually approached to participate the day following admission or the Monday following a weekend admission and then interviewed usually the following day after consenting to participate as per our ethics approval. Each participant has been given a number between 1 to 43 and quotes are linked e.g. participant 22 (P22)

Table of participants (see table 1 - insert about here).

Themes

The analysis of the data led to the identification of the following themes.

Symptoms

- Typical vs atypical presentations
 - Atypical presentations
- Absence of pain

Attribution and consequences

- Attributing symptoms to co-morbidities
 - Ascribing symptoms to DM
 - Ascribing symptoms to hypoglycaemia
- Delay in seeking help and gradual onset of symptoms
 - Multiple symptoms
- Lack of awareness of MI symptoms or their increased risk of MI
 - Experience of repeat MIs
- Language of pain
- Knowing something was wrong

However, these themes are not distinct. The nature of obtaining patients' narratives means that there are complex, inseparable relationships in concepts and ideas, with a continuum across themes and subthemes.

Symptoms

Typical versus atypical presentations.

Chest pain of a specific character is regarded as the classic symptom of MI and was present in most of these interviews:

"It was like your chest was being crushed." (P3)

Many of these descriptions catch this essence of a typical MI

"Err a real dull ache and like someone is screwing up, like a tight chest just really tight, like someone is squeezing it inside....yeah like a really, really dull pain"... "it started hurting and made me feel really ill ...but then I went really pale & started sweating .. absolutely saturated.. just a really tight chest and sore like, as if there was a weight directly on top of me". (P 11)

Most of those in the study experienced some typical symptoms. However, typical symptoms with a recent chronology (necessary to suspect MI) was not always present or immediately apparent in the interviews.

Some experienced sweating; regarded as a typical MI symptom.

"My night clothes were soaking wet." (P3).

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3 Breathlessness was also experienced either with pain or separately, which although
4 classed as a “typical” symptom [23], is not generally recognised by clinicians to be
5 suggestive of an MI.
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9 *“I can’t breathe, you couldn’t breathe, my wife she phone a medic ... No you*
10 *got the pain and you can’t breathe...you think you’re gonna die for the lack of*
11 *breath”, (P14)*
12

13
14 *“Like somebody’s pushing me...and I’m short of breath and then it was getting*
15 *worse and it start burning”. (P35)*
16
17

18 Atypical pain

19
20
21 Some of those in this study sometimes narrated their experience of a diffuse and
22 ambiguous set of symptoms that may not raise suspicion of MI.
23

24
25 *“It feels like something crawling up my arm... and it bites deep in there...the*
26 *only way I can describe it, it feels like someone is in there with claws and*
27 *they’re tearing at your inside. Just screaming and pulling at it. Very, very*
28 *strange pain indeed”, (P24)*
29
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32
33 although this person later describes quite typical sounding symptoms. Others
34 described the quality of their pain.
35

36
37 *“It was just sticking pain, it was just a really pain, stay there for about 3*
38 *hours”, (P30)*
39

40
41 *“Like a normal pain, it wasn’t a pain, actually it was dull”. (P26)*
42

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44 These quotes raise the issue of participants’ use of language which is discussed
45 later.
46

47
48 The following quote illustrates a mixture of some typical and atypical symptoms,
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50
51 *“I can feel something happening you know, my chest, had very bad pain in my*
52 *arm, my neck and my leg, I couldn’t move... Yeah sharp pain, very sharp*
53 *...Somebody was pressing my, you know, chest...My back... All the way up to*
54 *the waist...I couldn’t breathe you know. I get very deep breath, I tried to do it*
55 *but it didn’t go, somebody was choking me”. (P5)*
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3 The inseparability of these two types of symptoms (typical/ atypical) is raised in the
4 discussion.
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7 Symptoms of weakness and tiredness were also reported around the timing of the
8 MI. One participant could not walk and said:
9

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11 *"It's just the sheer um lethargy really, I just couldn't do anything...I wasn't*
12 *giddy and I wasn't in a lot of pain, I just couldn't sort of come too, I was, I*
13 *couldn't put one foot in front of the other. I was just so weak". (P10)*
14
15

16 17 Absence of pain

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19 Some clearly stated they had no chest pain;
20

21
22 *"Nothing, nothing, no discomfort, no pain" (pre cardiac arrest), (P27)*
23

24 but this participant did have pain after being resuscitated. Another reported
25

26
27 *"No pain, no sweating, nothing else" (pre cardiac arrest). (P23)*
28

29 Both of these participants experienced cardiac arrests, so some degree of event
30 amnesia cannot be excluded.
31

32 33 Attribution and consequences

34 35 Attributing symptoms to co-morbidities

36
37 The participants seemed to rationalise their symptoms and find a reason to dismiss
38 that the cause of their symptoms could be a "heart attack". Many attributed their
39 symptoms to other illness and causes. Most commonly, they attributed their
40 symptoms to indigestion, but the symptoms were attributed to other causes that
41 included asthma, muscular aches, panic attacks, stress and importantly in this group,
42 their DM.
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48
49 *"Because of, I have other illness(es), like blood pressure, diabetes, I didn't think*
50 *(of MI), because I thought there is nothing wrong with my heart." (P4).*
51
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53 There were recurrent attributions by participants of chest pain to indigestion leading
54 to self-medication with antacids for this.
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3 *“when you feel bloated and gassy and it’s similar to that sort of pain. That’s*
4 *why I mistook it for being indigestion.... I put it down to nerves or exercise*
5 *...but then in the early hours of Sunday morning I realised it couldn’t have*
6 *been indigestion because it was paining me a great deal”, (P31)*
7
8

9
10 *“I took, bicarb of soda, didn’t work. I took um Gaviscon (antacid remedy),*
11 *didn’t work. The antibiotics didn’t work. That’s when I knew, there was more to*
12 *this”. (P3)*
13
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15
16 These quotes link to the theme of delay (both by patient and clinician in this
17 instance) which is discussed further on.
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20 Ascribing symptoms to DM

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22 Participants sometimes attributed their symptoms to (lack) of control of their DM,
23 symptoms of DM or side effects of their medication.
24
25

26
27 *“I didn’t realise I was having heart attack, so I was feeling rotten ...I was*
28 *hungry. Well I wasn’t really hungry but I know, don’t, diabetic, ...that’s when*
29 *the pain come, and I went to bed and it woke me up around 2 in the morning”,*
30 *(P17)*
31
32

33
34 *“Well dizzy, tired, again I’m dizzy all the time with diabetes, you get that, that’s*
35 *part and parcel of being diabetic”. (P17)*
36
37

38 Participant 3 also attributed her dizziness during her MI to her DM:
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40
41 *“Not fainting, but you know dizzy turns, because I do get these dizzy turns.*
42 *You see, this is all in with the diabetes you see”. (P3)*
43
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45 Ascribing symptoms to hypoglycaemia

46

47 Patients when experiencing some symptoms, particularly sweating and feeling
48 unwell perceived themselves to be experiencing hypoglycaemia, for example:
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51
52 *“because I am diabetic, right, um, I thought, initially I thought it was um low*
53 *blood sugar”, (P2.)*
54
55

56 *“A little (of sweating) bit, but ...I didn’t have my testing gear with me & I*
57 *thought that it might be a hypo at the time”. (P11)*
58
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Participant 3 perceived herself to be experiencing hypoglycaemia,

"That's when I knew, there was more to this (symptoms) and I had, I don't know whether I had five hypo's in that week, but I was rolling all over the place". (P3).

Delay in seeking help and gradual onset of symptoms

Delay in help seeking was a prominent feature in these narratives.

"I think to be honest it (chest pain) came on suddenly but I tended to ignore it, I've got one more screw to put in", (P21)

"I waited till my GP opened in the morning. I called him and I told him what's wrong, they said 'just phone the ambulance' ". (P5).

This delay could be ascribed to participants' pre-existing angina; but participants often realised that something more serious was occurring when their symptoms did not improve.

"But it was there too long, so I said 'could be heart attack' ". (P30)

However, for some participants part of this delay was the gradual rather than sudden onset of symptoms.

"Well no ...it had happened a fortnight before"... "Sat in the chair for about 20mins and then it went so then I said to my wife, I told her 'If it happens again I would be calling the doctor' ". (P20)

Often participants had dismissed or explained away these one off or minor symptoms and did not think much of them, except with hindsight.

"more during the week. Nothing sharp... it was just a niggling thing, it just came and then it went away ... you just didn't think too much of any of these factors in isolation; but together". (P31)

With others, denial was behind their delay,

"Well I thought it was a heart attack but I didn't really want to admit it at the time. Anything other than a heart attack". (P17)

Multiple symptoms

The respondents often had complex narratives where chest pain was often a part of the symptom complex they describe, but their chest pain symptom may not have been the most prominent, important or distressing feature; which is exemplified by the following quote.

"It (chest pain) did come on suddenly ...at the same time I had this very heavy perspiration...& this very uncomfortable tummy ache...Err all three things hitting me at once; you don't pick one out in particular ...all those three factors the er tummy ache the excessive err sweating and the pain in the chest um I could point to one and say look that was the main problem.. they were all a problem at that short period of time". (P 25)

Lack of awareness of MI symptoms or their increased risk of MI

Many of these respondents, despite having long standing diabetes, previous cardiac events or a strong family history, seemed unaware that they were at a high risk of subsequent MI.

"My father had a heart attack, he died from it. My mother had a triple heart bypass. My elder brother's had an angioplasty, so it does run in the family."
(P2)

Experiences of a repeat MI

Participants who had previous MIs might be expected to have a good working knowledge of these symptoms and respond accordingly if it recurred but did not necessarily do so.

"I should have guessed, right, um, it's exactly the same symptoms as when I had my first heart attack". (P2)

Language of pain

The expectation of severe chest pain is key to many patients' and doctors' model of what an MI should be like and is apparent in some previous themes. However, many

1
2
3 of these respondents had symptoms that they didn't feel reached a threshold of
4 severity that they would call "pain".
5
6

7 *"I suppose people would call it a pain, I don't know, I wouldn't, I would still call*
8 *it severe discomfort...dull, rather than, no it wasn't sharp.... I won't put it (pain*
9 *severity score) higher, otherwise I probably would have called an ambulance*
10 *straight away", (P20)*
11

12
13
14 *"No, it was a constant. When I say pain, ache, it wasn't a pain that was*
15 *making me double up or anything". (P25)*
16
17

18 While some struggled to conceptualise their symptoms as pain, others struggled to
19 use words to describe their symptoms
20
21

22
23 *"It's so difficult cos it was more uncomfortable than a pain that you can*
24 *describe ... I don't know how to describe it". (P20)*
25
26

27 While others clearly had very significant pain but still struggled to articulate it.
28

29 *"Indescribable to me, I couldn't, as I sit here I can't describe it... I had severe*
30 *pain and it was; I don't know how you break it down into words". (P19)*
31
32

33 Knowing something is "wrong"

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35
36 Frequently participants had a "gut feeling" that there was something wrong or a
37 strong emotional response to their symptoms.
38
39

40 *"You know, I could sort of feel that there was something wrong", (P2).*
41

42 *"And I thought I can't do this, I got to get 'elp, and that's when I dialled 999...*
43 *and, you know, everything was going wrong, and I just couldn't figure out".*
44 *(P3).*
45
46
47

48 A "sense of doom" is often associated with the presentation of MI, but in this group
49 only one participant reported a strong sense of impending death.
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52 *"I felt as if I was going to die (anxious voice)". (P6)*
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Discussion

We found that patients with DM who experienced an MI exhibited a wide range of symptoms from very classical presentations to very mild symptoms. Patients often were unclear what caused their symptoms. This diagnostic confusion or uncertainty appears periodically to have been mirrored by clinicians.

The symptoms experienced in this group ranged from those that may be expected by health care professionals, to more atypical symptoms with patients using unusual descriptive terms. The variation in experiences highlights the difficulty for both patients and healthcare providers to correctly attribute these symptoms to a cardiac event.

Patients with DM will often have other significant co-morbidities which can be attributed to their symptoms e.g. breathlessness from chronic obstructive pulmonary disease (COPD) rather than an MI. However, there seems to be an important area of confusion from symptoms related to DM and its control, that can lead to a misattribution of pain symptoms away from a new onset MI. A specific issue among this group is the impact of MI symptoms which were perceived as a side effect of medication (particularly insulin and oral hypoglycaemics). Interpreting episodes of hypoglycaemia and sudden onset MI seems to be particularly challenging with an overlap of many similar symptoms and their sudden onset.

We found a lack of knowledge of MI symptoms, being falsely reassured by lack of severe pain or not conceptualising milder chest discomfort as chest pain. These factors may all lead to denial or confusion and therefore delay in seeking care.²⁸ Delay in seeking medical attention during an MI, will have significant prognostic implications.

As the participants' symptoms did not fit with their preconceived ideas of an MI, they ascribed it to other less serious causes, or importantly attributed their symptoms to their DM, medication side effects or "hypos"; which is a novel and important finding. The attenuated chest pain competing with other, perhaps more distressing symptoms and so being "crowded out" from the illness cognition of a possible MI, has not been previously reported.

Strengths

Within this study we have reported contemporaneous symptoms from a well described patient group, who can be characterised by their MI diagnosis. We have captured a wide range of participants with MI, by using biochemical confirmation of diagnosis wherever possible, but also by including clinical diagnoses (e.g. for cardiac arrests). Unusually for a qualitative study we have a relatively large number of participants, who were interviewed as early as possible (or allowed to) after the event to reduce recall bias.²⁹

Limitations

Despite recruiting participants on the basis of their MI diagnosis, but not specifically on chest pain presentations, participants are likely to have initially volunteered chest pain symptoms to get admitted to a coronary care unit. Markedly discrepant MI narratives are less likely to be represented in this study, as are silent MIs, as they are more likely to go unrecognised and present late. Survivor bias is also a distinct possibility. While a study size of 40 is good for qualitative research,²⁹ it is small in comparison with epidemiological studies so this methodology is therefore unlikely to pick up rarer presentations of MI.

Recruiting on the basis of being able to converse in English will exclude the linguistic nuance of other languages and cultures; important when south Asian populations among others, have a high risk of DM and coronary heart disease. However, we did successfully capture many patients who had English as second language. Additionally the UK NHS struggles to provide reliable, accessible translation; particularly in the acute and out of hours setting, so our findings may more faithfully reflect the real world setting of these decisions and presentations.

Truncating these interviews into quotes also runs the danger of falsely dichotomising symptoms into “typical” and “atypical”. When the transcripts are read in full and in context, a more rounded picture of the event develops. This nuanced view is

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2
3 probably a key element that helps experienced clinicians successfully identify a
4 potential MI, in this group of patients.
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10 How this fits into existing literature
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12 The findings of our study link with previous work within a broad context of
13 psychological models of illness behaviour such as the health belief model.³⁰
14 Theoretical models of delay in seeking treatment specifically in relation to MI have
15 been summarised by Dracup.²⁸ Other studies highlight the considerable
16 psychological impact of pain and specifically cardiac pain³¹, where cardiac
17 symptoms can be interpreted as pain, but also can trigger symptoms such as anxiety
18 and responses like uncertainty³² leading to denial and fear.³³ The response of
19 denial is well recognised in other studies, particularly among men, where the impact
20 of their gender roles can adversely affect their health seeking behaviour.³⁴ Many of
21 our participants did not perceive themselves to be at risk of a heart attack. The
22 perceived lack of vulnerability to heart disease links to the concept of “lay
23 epidemiology” and of “coronary candidacy” i.e. not fitting assumptions about the sort
24 of person who gets a heart attack.³⁵
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34 The language of describing pain and particularly the difficulty of describing pain
35 recurs within our sample. Scarry describes this as the “inexpressibility of pain”³⁶ and
36 this is seen with some respondents. Others use metaphor and simile to circumvent
37 this issue, which may be helpful to the patient but means a clinician might cognitively
38 process such symptom descriptions as “atypical” or “non cardiac”, leading to delays
39 in treatment. The term “chest pain” is also problematic¹⁸; many of these participants
40 did not conceptualise their chest symptoms as pain and so, Miller has suggested
41 using the term “chest sensation” instead.³⁷
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48 We have used our findings to adapt Rosenstock and Kirsch’s health belief model
49 (see figure 1) so that the impact of DM can modify the steps in the model such as
50 reduced pain from neuropathy during an MI reducing the likelihood of action.
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57 Diagram here (figure 1)
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Our findings have some similarities to other studies about patients' experiences of MI.^{23 38 39 40} The similarity of symptom presentation raises the possibility that these studies are just capturing the heterogeneous array of MI symptoms and this is unlinked to any underlying physiological or pathological process such as gender or DM. However, our finding of patient misattribution of MI symptoms to DM and diabetic medication, in a group at high risk of MI, does have significant clinical implications for patients and clinicians.

Implications for further research

Despite knowing that people with DM are at much higher risk of coronary events we fail to inform patients in the UK about their increased cardio vascular risk nor identify early those who may be developing such problems. Whether screening diabetics for ischaemic heart disease would be beneficial remains a key question. Possibilities include trialling patient education about their CHD risk and its presentation in the UK Quality and Outcome (QOF) DM check or including this information within DESMOND (desmond-project.org.uk)/DAFNE (www.dafne.uk.com) patient education programmes, but there would be considerable difficulty in designing an educational package that could reliably help patients distinguish between these two aetiological possibilities of "hypo" versus MI.

Implications for practice

This study could contribute towards increased awareness of MI in those with DM. Clinicians should carefully explore patients' symptoms as well as their interpretation of their symptoms. Patients with DM should be made aware of their increased risk of cardiac events, how they present and how they differ from medication side effects and "hypos".

a. Contributorship statement

All 3 authors fulfil all three of the ICMJE guidelines for authorship, MJ had the original study conception and design and then supervised NT during her iBSc project. NT collected all the data. NT and DDC analysed the final data set. MJ wrote the final manuscript with substantial intellectual input from NT and DDC. All authors approved the final manuscript.

b. Competing interests

None

c. Funding

Royal College of General Practitioners' Scientific foundation board (grant SFB 2011-25)

d. Data sharing statement

No additional data are available as participants only consented to quotes being published.

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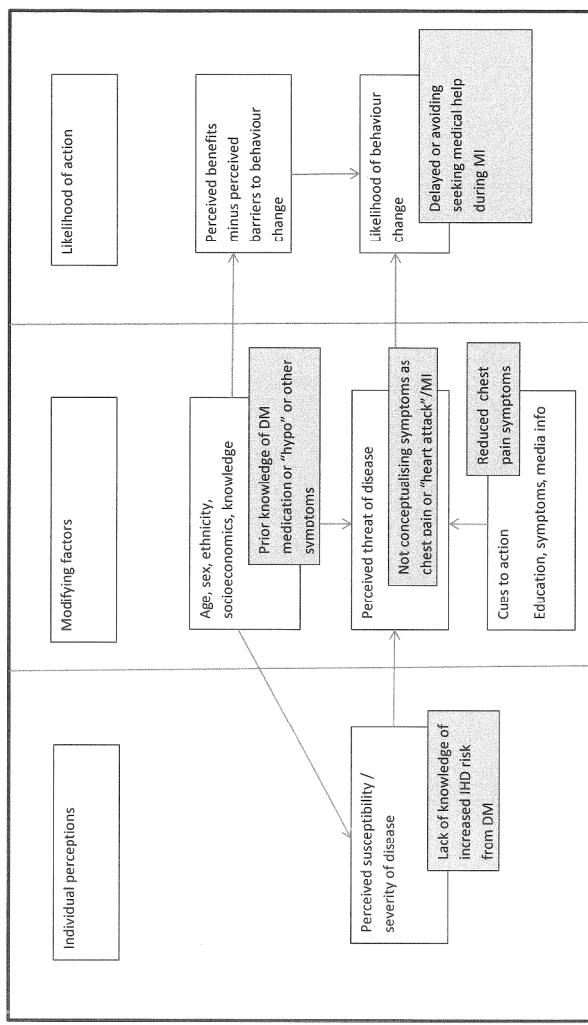
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Figure 1: How diabetes (grey boxes) might affect the "Health Belief model" during MI
 With permission from Fig 1, page 115 (adapted) from Victor J. Strecher and Irwin M. Rosenstock, "The health belief model", Andrew Baum, Stanton Newman, John Weinmar, Robert West, Chris McManus (eds.), (1997), "Cambridge Handbook of Psychology, Health and Medicine, 9780521436861, Cambridge : Cambridge University



Caption : How diabetes (grey boxes) might affect the "Health Belief model" during MI

296x419mm (300 x 300 DPI)

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Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No	Item	Guide questions/description	Author completed
Domain 1: Research team and reflexivity			
	Personal Characteristics		
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	NK
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	MD MSc (MH) undergraduate (NK), BSc (DDC)
3.	Occupation	What was their occupation at the time of the study?	Sen Lect (MJ), MB BS / iBSc student (NK), student/junior doc (DDC)
4.	Gender	Was the researcher male or female?	Both genders
5.	Experience and training	What experience or training did the researcher have?	MJ extensive research and research supervision, NK / DDC developed expertise dug study
Relationship with participants			
6.	Relationship established	Was a relationship established prior to study commencement?	no
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	Information as set out in pt info leaflet as agreed by IRC/ ethics committee
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	NK identified as medical student, MJ as academic and clinician
Domain 2: study design			
Theoretical framework			

No	Item	Guide questions/description	Author completed
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	Thematic analysis (Ritchie and Spencer)
	Participant selection		
10.	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>	convenience
11.	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>	Prior selection by clinical team (to establish well enough to participate), approach with PIS by researcher, and "cooling off" period
12.	Sample size	How many participants were in the study?	43
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	
	Setting		
14.	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	On hospital ward (including coronary care unit)
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	Occasionally patient relatives stayed during the interview.
16.	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	Recorded in table 1 of manuscript
	Data collection		
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Yes
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio-recorded
20.	Field notes	Were field notes made during and/or after the interview or focus group?	Yes
21.	Duration	What was the duration of the interviews or focus group?	5-48 minutes

No	Item	Guide questions/description	Author completed
22.	Data saturation	Was data saturation discussed?	Yes
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No as no identifiable data was removed from the ward
Domain 3: analysis and findingsz			
Data analysis			
24.	Number of data coders	How many data coders coded the data?	2
25.	Description of the coding tree	Did authors provide a description of the coding tree?	Thematic analysis was recorded as an excel spreadsheet not a tree
26.	Derivation of themes	Were themes identified in advance or derived from the data?	Data derived
27.	Software	What software, if applicable, was used to manage the data?	Spreadsheet and word processing software
28.	Participant checking	Did participants provide feedback on the findings?	No (see previous comments)
Reporting			
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>	Yes identified by participant number.
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes
31.	Clarity of major themes	Were major themes clearly presented in the findings?	Yes
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes

BMJ Open

"Just like a normal pain"- experiences of people with diabetes mellitus recruited from hospitals after having a myocardial infarction - a qualitative study

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2016-015736.R1
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Primary Subject Heading:	Cardiovascular medicine
Secondary Subject Heading:	Diabetes and endocrinology, Qualitative research, Emergency medicine, General practice / Family practice
Keywords:	Chest pain, Myocardial infarction < CARDIOLOGY, Diabetic nephropathy & vascular disease < DIABETES & ENDOCRINOLOGY

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8 **“Just like a normal pain”- experiences of people**
9 **with diabetes mellitus recruited from hospitals after**
10 **having a myocardial infarction - a qualitative study.**
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Abstract

Objective: The objective of the study was to investigate the symptoms people with diabetes experience when having a myocardial infarction (MI), their illness narrative, and how they present their symptoms to the health service.

Setting: Three London (United Kingdom) hospitals- Coronary care units (CCU) and medical wards.

Participants: Patients were recruited with diabetes mellitus (DM) (Type 1 & 2) with a clinical presentation of MI (ST elevated myocardial infarction [STEMI], non ST elevated myocardial infarction [NSTEMI], acute MI unspecified & cardiac arrest). 43 participants were recruited, 39 interviews met the study criteria and were analysed. They were predominantly male (n=30), aged 40-90 years and white British (18/39), just over a half were from other ethnic groups. The majority had type II DM (n=35); 24 had an NSTEMI, 10 had an STEMI and 5 had other cardiac events.

Definitions of selection / exclusion criteria: a diagnosis of MI, and DM, the ability to communicate enough English to complete the interview. Ward staff made a clinical judgement that the participant was post-treatment, clinically stable and well enough to participate.

Methods: A qualitative study utilising taped and transcribed interviews analysed using a thematic analysis.

Results: While most participants did experience chest pain, it was often not their most striking symptom. As their chest pain did not match their expectations of what a "heart attack" should be, participants developed narratives to explain these symptoms, including the symptoms being effects of their DM ("hypos"), side effects of medication (oral hypoglycaemics) or symptoms (such as breathlessness and indigestion) related to other comorbidities; often leading to delays in seeking care.

Conclusions:

While truly absent chest pain during MI among people with DM was rare in this study, patients' attenuated symptoms often led to delay in seeking attention, and this may result in delays in receiving treatment.

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3 **Data sharing:** - No additional data available.
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6 **Article summary**
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8 Strengths and weaknesses
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11 This is a study of people with diabetes experiencing an MI.
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13 Strengths of the study include:
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- 15 • contemporaneous patients' descriptions of their symptoms and illness
16 narrative just after an MI,
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- 18 • a model of how attenuated MI symptoms might alter help seeking behaviour,
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- 20 • the participants were from a wide demographic background in terms of age,
21 ethnicity and disease burden.
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24 Weaknesses include:
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- 26 • by recruiting patients from coronary care units we will not have captured
27 markedly discrepant presentations,
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- 29 • by recruiting on the basis of the ability to communicate in English we will have
30 lost some cultural and linguistic nuance in symptom presentation.
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Background

Diabetes Mellitus (DM) is a common health problem worldwide and affects 4-6% of the UK population.¹ Cardiovascular disease (CVD) is the major life threatening complication of DM in the UK.^{2 3 4} Myocardial infarction (MI) is the prime cause of excess mortality among those with DM, with a 3-fold increased risk of coronary heart disease (CHD) mortality,^{5 6} a 6-fold increased risk of myocardial infarction (MI)⁷ and a worse prognosis from MI compared with populations without diabetes.⁸

Possible mechanisms of this excess mortality risk include comorbidities such as hypertension, dyslipidaemia and chronic kidney disease. An important element in this observed increased mortality may be late or missed presentation by patients, and diagnosis by clinicians.^{9 10 11}

Up to a third of people who suffer an MI can have no chest pain; however people with DM make up a larger proportion of this group (32.6% vs 25.4% in one study).¹² However, when people with DM do have symptoms of an MI, their symptoms may often be atypical¹³ or unusual.¹⁴ Nevertheless, there is conflicting evidence around this issue: Funk found no statistically significant difference in CHD symptom presentation in people with and without DM, but did report non-significant increases in dyspnoea, neck and throat pain among those with DM.¹⁵ Kentsch found no differences between these groups in the frequency or severity of chest pain but also identified differences in the prevalence of dyspnoea.¹⁶ One review found conflicting results about differing MI symptoms among women with and without DM.¹⁷

There are several methodological reasons why these studies may have conflicting results: being underpowered,^{18 19} being unrepresentative of the population at risk,¹⁸ or recruited from highly selected hospital populations.²⁰ Survivor bias (i.e. living to tell the tale of your symptoms) may also be an important issue in a condition such as MI which has a high early mortality.²¹

There is a biological basis for altered perception of pain among people with diabetes in that cardiac autonomic neuropathy (CAN) is a complication of DM and leads to

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3 altered pain perception, meaning a patient might not experience pain caused by
4 myocardial ischaemia.²⁰
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7 Several qualitative studies have explored patients' symptoms during MI.^{22 23 24 25 26}

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9 ¹⁸ Within the general population experiencing MI, there are several issues identified
10 including; the considerable psychological impact of pain and specifically cardiac
11 pain,²⁷ cardiac symptoms that can be interpreted as pain, but also can trigger
12 symptoms such as anxiety (both as a trigger and barrier to action) and fear,²⁸
13 producing responses like uncertainty,²⁹ and denial.³⁰ Further factors identified
14 include patients not recognising their symptoms as MI, experiencing vague
15 symptoms,³¹ misattributing their symptoms,^{23 24} erroneous expectations of an MI,
16 ³¹ and the decisions patients make during their MI.³² Other factors include delays in
17 seeking care.^{30 11} Theoretical models of delay in seeking treatment specifically in
18 relation to MI have been summarised by Dracup.³³ Underestimating personal risk of
19 an MI,²³ and perceived lack of vulnerability to heart disease link to the concept of
20 "lay epidemiology" and of "coronary candidacy" i.e. not fitting assumptions about the
21 sort of person who gets a heart attack.³⁴
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31 There is a role of gender with MI symptoms and its interpretation; work exploring
32 women's experience of MI symptoms found that women with diabetes had more
33 atypical and painless MIs than men.³⁵ In studies of denial among men, there has
34 been exploration of the impact of their gender roles adversely effecting health
35 seeking behaviour.³⁶
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40 In studies specifically exploring the experience of patient with diabetes and MI, many
41 similar themes emerge. However Angerud finds a variability in the experience of MI
42 symptoms while exploring the patients' response to symptoms, perceived
43 susceptibility, and symptom interpretation (but found that MI symptoms were rarely
44 ascribed to DM).²⁵ Other studies in this population also identify breathlessness as a
45 presenting symptom, misinterpretation of symptoms; and their diabetes influencing
46 patients' decision making during events.³⁷
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53 Clinician factors
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3 The way clinicians ask about chest symptoms may be problematic. Clinicians ask
4 about “chest pain”, however the term “pain”,^{38 39} is often not used by patients
5 experiencing MI.
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9 In the current study, we aimed to address some of the limitations of previous
10 research by recruiting only DM patients with clear evidence of a recent MI,
11 regardless of their chest pain presentation, and use of a qualitative methodology to
12 explore how these patients describe their symptoms. Qualitative methods can help
13 overcome a narrow clinician focus and help develop a patient orientated view when
14 exploring symptoms of disease.^{37 40 23 41} The aim of the study was to investigate
15 the symptoms people with diabetes experience when having a myocardial infarction,
16 their illness narrative, and how they present their symptoms to the health service.
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Methods

This was a qualitative study where interviews were undertaken with a patients with DM who have recently had a confirmed MI, recruited within coronary care units (CCU). Eligibility criteria included a confirmed diagnosis of MI (according to AHA criteria ⁴²), a clinical diagnosis of DM and the ability to communicate (understand and speak) enough English to complete the interview. Clinical staff identified participants and ensured they were post-treatment, clinically stable and well enough to participate. This subjective judgement was made by the clinical staff involved in participants' care as required by the ethics committee. Participants were approached as soon as possible after the diagnosis by a researcher (NB) so we could be sure that they had had an MI (usually a retrospective or working diagnosis) and to minimise recall bias about symptoms. Once invited, they were given a patient information sheet (PIS) about the study and 24 hours to decide whether to participate (see comments regarding ethics approval). The interviews took place in three London, UK hospitals. We aimed to recruit consecutive patients (but this proved unworkable) so this was a pragmatic sample. ⁴³

The interviews were semi-structured and iterative building from a topic guide to include a narrative of the course, range, character and severity of the symptoms the person experienced before and during their MI. A checklist of AMI symptoms based on Funk's acute myocardial infarction (AMI) symptom list ¹⁵ This is distinct to Diamond and Forrester's classification of angina typicality.⁴⁴ The checklist was worked through to ensure symptoms were absent and not just omitted. Ideas about expected symptoms of an MI, and symptom attribution were also explored as people often develop complex narratives about their illnesses. ⁴⁵ We also explored participants' thoughts about their illness, treatments they had attempted, motives and triggers for seeking help, awareness and knowledge of the symptoms of a heart attack.

Interviews were audio recorded, field notes and baseline patient information were noted. Details gathered included the type of MI (ECG changes, troponin level, clinical assessment), the patients' demographics, co-morbidities (type and duration of DM,

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2
3 other disease), risk factors, family history, medication use and information that might
4 impact on symptom perception, from the informant and their medical records. All
5 participants were allocated a code number to link their data together and then
6 anonymised (apart from the consent form) so that identifiable data did not leave the
7 ward setting.
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12 The audio taped interviews were transcribed verbatim and manually analysed using
13 a thematic framework approach,^{22 46} using word processing and spreadsheet
14 software. Agreement was specifically sought between reviewers about the
15 classification of symptoms as either typical or atypical as outlined by Funk.¹⁵ Two
16 independent researchers (NB, DDC) read the transcripts and analysed the data
17 using the following steps: familiarisation, identifying a thematic framework, indexing,
18 charting, mapping and interpretation. Throughout this process, transcripts were
19 repeatedly re-read to focus on specific points and ideas, to verify the presence of the
20 themes that are identified and ensure the context of the themes has been preserved.
21 There was then a dialogue between all the researchers which was reflexive in nature
22 linking the findings back to the study's aims. The analysis was deductive or
23 theoretical in approach in that we were looking for themes around diabetes and
24 myocardial infarction, and bounded by an expectation of probable reduced or absent
25 pain symptomatology and this shaped our topic guide and approach to the data.
26 However, the analysis was also inductive in nature, in that we needed to derive
27 themes from the data, in as much that if there were no pain symptoms during the MI,
28 we needed the participants and their narratives to tell us what they did experience.
29 The themes around reporting of symptoms is semantic (or a surface meaning) in that
30 we are largely reporting the participants' descriptions of their experience. However,
31 the explanatory models around what participants thought caused their symptoms
32 and reactions to those symptom is a much more latent thematic or interpretive
33 analysis.²² Representative quotes (with consent) were used and have identifying
34 details to link the theme to the participants' characteristics.
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51 The lay term "heart attack" is used extensively in the transcripts; this can have a
52 broad popular meaning but we will assume is used by participants to suggest a
53 myocardial infarction.
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3 Ethical approval for this study and the use of quotes was obtained from the
4 Hertfordshire Research Ethics Committee. (Project no: 11/EE/0045). The committee
5 requested that we allowed a “cool off” period of 24 hours from approach to obtaining
6 consent. Data protection and local hospital trust R&D policies were followed.
7
8 Consent was not originally sought to disclose the full interview transcripts.
9
10

11 Patient involvement

12
13
14 The original idea for this study was based on a clinical encounter in general practice.
15 A patient consulted MJ his GP, having suffered a severe MI despite having minimal
16 symptoms and subsequently developed severe heart failure. Before his death, this
17 patient agreed to support research in this area and filmed a brief video of his
18 experiences. A broader study (with same research question but a different
19 methodology) on this field was presented and supported by the North East London
20 Diabetes Research Network Lay Panel Meeting in 2011. Patients’ narratives
21 constitute the data underlying this study.
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Results

Forty three participants were recruited from the participating hospitals, however 4 interviews proved unusable due to not meeting study recruitment criteria on detailed case review and were excluded, resulting in a total of 39 participants' data available for analysis. The interviews had a mean duration of 20mins 33 sec (with a range of 5 mins 14 secs to 48mins 46 secs) and were all undertaken by one interviewer; NB. The study comprised of 30 men and 9 women; with an age range of 40-90, 35 participants had type 2 DM and 4 had type 1 DM. All participants had confirmed acute coronary syndrome; 24 had NSTEMIs, 10 had STEMIs and 5 had other MIs (acute MI-unspecified including 4 cardiac arrests). Their ethnic categories were White British (n=18), Asian/ south Asian (n=7), African or Afro-Caribbean (n=3) and others (n=5) e.g. Turkish, Maltese etc. A number (n=6) declined to state their ethnicity or instead identified their religious affiliation e.g. "Church of England", "Jewish" etc. One interview was done via an informal family translator but frequently family members would participate in the interview, clarifying the order of events or reminding the participant about elements of their illness narrative (which may have been clouded by their illness including cardiac arrest or treatment such as strong opioid analgesics). Participants were usually approached to participate the day following admission, or the Monday following a weekend admission and then interviewed usually the following day after consenting to participate as per our ethics approval. Data saturation was achieved. Each participant was given a study number between 1 to 43 and quotes are linked e.g. participant 22 (P22)

Themes

The analysis of the data led to the identification of the following themes and sub themes.

Symptoms

- Typical vs atypical presentations
 - Atypical presentations
- Absence of pain

Attribution and consequences

- Attributing symptoms to co-morbidities
 - Ascribing symptoms to DM
 - Ascribing symptoms to hypoglycaemia
- Delay in seeking help
- Gradual onset of symptoms
 - Multiple symptoms
- Lack of awareness of MI symptoms or their increased risk of MI
 - Experience of repeat MIs
- Language of pain
- Knowing “something was wrong”

However, these themes are not distinct. The nature of obtaining patients’ narratives means that there are complex, inseparable relationships in concepts and ideas, with a continuum across themes and subthemes.

Symptoms

1
2
3 Participants described a wide range of symptoms, primarily around chest pain and
4 discomfort. However, other symptoms associated with MI such as sweating and
5 breathlessness were described, as well as a series of symptoms that are not usually
6 associated with MI presentations. With regard to chest pain, we found a range of
7 symptom presentations.
8
9

10 11 Typical versus atypical presentations.

12
13 Chest pain of a specific character is regarded as the classic symptom of MI and was
14 present in most of these interviews;
15
16

17
18 *“It was like your chest was being crushed.” (P3)*
19

20
21 Many of these descriptions catch this essence of a typical MI;
22

23
24 *“Err a real dull ache and like someone is screwing up, like a tight chest just
25 really tight, like someone is squeezing it inside....yeah like a really, really dull
26 pain”... “it started hurting and made me feel really ill ...but then I went really
27 pale & started sweating .. absolutely saturated.. just a really tight chest and
28 sore like, as if there was a weight directly on top of me”. (P 11)*
29
30
31

32
33 Most of those in the study experienced some typical symptoms. However, typical
34 symptoms with a recent chronology (necessary to suspect MI) was not always
35 present or immediately apparent in the interviews.
36
37

38
39 Some experienced sweating; regarded as a typical MI symptom;
40

41
42 *“My night clothes were soaking wet.” (P3).*
43

44
45 Breathlessness was also experienced either with pain or separately, which although
46 classed as a “typical” symptom [23], is not generally recognised by clinicians to be
47 suggestive of an MI;
48

49
50 *“I can’t breathe, you couldn’t breathe, my wife she phone a medic ... No you
51 got the pain and you can’t breathe...you think you’re gonna die for the lack of
52 breath”, (P14)*
53

54
55 *“Like somebody’s pushing me...and I’m short of breath and then it was getting
56 worse and it start burning”. (P35)*
57
58
59
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Atypical pain

Some of those in this study sometimes narrated their experience of a diffuse and ambiguous set of symptoms that may not raise suspicion of MI;

"It feels like something crawling up my arm... and it bites deep in there...the only way I can describe it, it feels like someone is in there with claws and they're tearing at your inside. Just screaming and pulling at it. Very, very strange pain indeed", (P24)

although this person later describes quite typical sounding symptoms. Others described the quality of their pain;

"It was just sticking pain, it was just a really pain, stay there for about 3 hours", (P30)

"Like a normal pain, it wasn't a pain, actually it was dull". (P26)

These quotes raise the issue of participants' use of language which is discussed later.

The following quote illustrates a mixture of some typical and atypical symptoms;

"I can feel something happening you know, my chest, had very bad pain in my arm, my neck and my leg, I couldn't move... Yeah sharp pain, very sharp ...Somebody was pressing my, you know, chest...My back... All the way up to the waist...I couldn't breathe you know. I get very deep breath, I tried to do it but it didn't go, somebody was choking me". (P5)

The inseparability of these two types of symptoms (typical/ atypical) is raised in the discussion.

Symptoms of weakness and tiredness were also reported around the timing of the MI. One participant could not walk and said;

"It's just the sheer um lethargy really, I just couldn't do anything...I wasn't giddy and I wasn't in a lot of pain, I just couldn't sort of come to, I was, I couldn't put one foot in front of the other. I was just so weak". (P10)

Absence of pain

1
2
3 Some clearly stated they had no chest pain;

4
5 *“Nothing, nothing, no discomfort, no pain” (pre cardiac arrest), (P27)*

6
7
8 but this participant did have pain after being resuscitated. Another reported;

9
10 *“No pain, no sweating, nothing else” (pre cardiac arrest). (P23)*

11
12 Both of these participants experienced cardiac arrests, so some degree of event
13 amnesia cannot be excluded.

14 15 16 17 Attribution and consequences

18 19 Attributing symptoms to co-morbidities

20
21 The participants seemed to rationalise their symptoms and find a reason to dismiss
22 that the cause of their symptoms could be a “heart attack”. Many attributed their
23 symptoms to other illness and causes. Most commonly, they attributed their
24 symptoms to other illness and causes. Most commonly, they attributed their
25 symptoms to indigestion leading to self-medication with antacids for this;

26
27
28
29 *“when you feel bloated and gassy and it’s similar to that sort of pain. That’s*
30 *why I mistook it for being indigestion.... I put it down to nerves or exercise*
31 *...but then in the early hours of Sunday morning I realised it couldn’t have*
32 *been indigestion because it was paining me a great deal”, (P31)*

33
34
35
36
37 *“I took, bicarb of soda, didn’t work. I took um Gaviscon (antacid remedy),*
38 *didn’t work. The antibiotics didn’t work. That’s when I knew, there was more to*
39 *this”. (P3)*

40
41
42 but symptoms were also attributed to other causes that included asthma, muscular
43 aches, panic attacks, stress and importantly in this group, their DM;

44
45
46
47 *“Because of, I have other illness(es), like blood pressure, diabetes, I didn’t think*
48 *(of MI), because I thought there is nothing wrong with my heart.” (P4).*

49
50
51 These quotes also link to the theme of delay (both by patient and clinician in this
52 instance) which is discussed further on.

53 54 55 Ascribing symptoms to DM

1
2
3 Participants sometimes specifically attributed their symptoms to (lack) of control of
4 their DM, symptoms of DM or side effects of their medication;
5
6

7 *"I didn't realise I was having heart attack, so I was feeling rotten ...I was*
8 *hungry. Well I wasn't really hungry but I know, don't, diabetic, ...that's when*
9 *the pain come, and I went to bed and it woke me up around 2 in the morning",*
10 *(P17)*
11
12

13
14 *"Well dizzy, tired, again I'm dizzy all the time with diabetes, you get that, that's*
15 *part and parcel of being diabetic". (P17)*
16
17

18
19 Participant 3 also attributed her dizziness during her MI to her DM;
20

21 *"Not fainting, but you know dizzy turns, because I do get these dizzy turns.*
22 *You see, this is all in with the diabetes you see". (P3)*
23
24

25 Ascribing symptoms to hypoglycaemia

26

27
28 Patients when experiencing some symptoms, particularly sweating and feeling
29 unwell perceived themselves to be experiencing hypoglycaemia ("Hypo"), for
30 example;
31
32

33 *"because I am diabetic, right, um, I thought, initially I thought it was um low*
34 *blood sugar", (P2.)*
35
36

37 *"A little (of sweating) bit, but ...I didn't have my testing gear with me & I*
38 *thought that it might be a hypo at the time". (P11)*
39
40

41
42 Participant 3 perceived herself to be experiencing hypoglycaemia;
43

44 *"That's when I knew, there was more to this (symptoms) and I had, I don't*
45 *know whether I had five hypo's in that week, but I was rolling all over the*
46 *place". (P3).*
47
48

49 Delay in seeking help

50

51
52 Delay in help seeking was a prominent feature in these narratives;
53
54

55 *"I think to be honest it (chest pain) came on suddenly but I tended to ignore it,*
56 *I've got one more screw to put in", (P21)*
57
58
59
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1
2
3 *"I waited till my GP opened in the morning. I called him and I told him what's*
4 *wrong, they said 'just phone the ambulance' ". (P5).*
5
6

7 This delay could be ascribed to participants' failure to attribute symptoms to MI,
8 attribution to co-morbidities, lack of symptom awareness or lack of awareness of
9 increased risk of MI; but participants often realised that something more serious was
10 occurring when their symptoms did not improve;
11
12

13
14 *"But it was there too long, so I said 'could be heart attack' ". (P30)*
15
16

17 Often participants had dismissed or explained away these one off or minor
18 symptoms and did not think much of them, except with hindsight;
19
20

21 *"more during the week. Nothing sharp... it was just a niggling thing, it just*
22 *came and then it went away ... you just didn't think too much of any of these*
23 *factors in isolation; but together". (P31)*
24
25
26

27 With others, denial was behind their delay;
28

29 *"Well I thought it was a heart attack but I didn't really want to admit it at the*
30 *time. Anything other than a heart attack". (P17)*
31
32
33
34
35

36 Gradual onset of symptoms

37

38 For some participants part of this delay was the gradual rather than sudden onset of
39 symptoms;
40
41

42 *"Well no ...it had happened a fortnight before"... "Sat in the chair for about*
43 *20mins and then it went so then I said to my wife, I told her 'If it happens*
44 *again I would be calling the doctor' ". (P20)*
45
46
47

48 Multiple symptoms

49

50 The respondents often had complex narratives where chest pain was a part of the
51 symptom complex they described, but their chest pain symptom may not have been
52 the most prominent, important or distressing feature; exemplified by the following
53 quote;
54
55
56
57
58
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1
2
3 *"It (chest pain) did come on suddenly ...at the same time I had this very heavy*
4 *perspiration...& this very uncomfortable tummy ache...Err all three things*
5 *hitting me at once; you don't pick one out in particular ...all those three factors*
6 *the er tummy ache the excessive err sweating and the pain in the chest um I*
7 *could point to one and say look that was the main problem.. they were all a*
8 *problem at that short period of time". (P 25)*
9
10
11
12

13 14 15 16 Lack of awareness of MI symptoms or their increased risk of MI

17
18 Many of these respondents, despite having long standing diabetes, previous cardiac
19 events or a strong family history, seemed unaware that they were at a high risk of
20 subsequent MI;
21
22

23
24
25 *"I thought ...how can I have a heart attack? Right. But you see, this might be*
26 *relevant as well; both my side of my family, my mother's side and my father's*
27 *side are diabetic. My father had a heart attack as well and he died from it. My*
28 *mother had a triple heart bypass. My elder brother's had an angioplasty, right,*
29 *so it does run in the family" (P2)*
30
31
32

33 34 Experiences of a repeat MI

35
36 Participants who had previous MIs might be expected to have a good working
37 knowledge of these symptoms and respond accordingly if it recurred. We found
38 however that often they did not do so;
39
40

41
42 *"I should have guessed, right, um, it's exactly the same symptoms as when I*
43 *had my first heart attack". (P2)*
44
45

46 Language of pain

47
48 The expectation of severe chest pain is key to many patients' and doctors' model of
49 what an MI should be like and is apparent in some of the previous themes. However,
50 many of these respondents had symptoms that they didn't feel reached a threshold
51 of severity that they would call "pain";
52
53
54

55
56 *"I suppose people would call it a pain, I don't know, I wouldn't, I would still call*
57 *it severe discomfort...dull, rather than, no it wasn't sharp.... I won't put it (pain*
58
59
60

1
2
3 severity score) higher, otherwise I probably would have called an ambulance
4 straight away”, (P20)
5
6

7 “No, it was a constant. When I say pain, ache, it wasn’t a pain that was
8 making me double up or anything”. (P25)
9

10
11 While some struggled to conceptualise their symptoms as pain, others struggled to
12 use words to describe their symptoms;
13

14
15 *“It’s so difficult cos it was more uncomfortable than a pain that you can
16 describe ... I don’t know how to describe it”. (P20)*
17
18

19 While others clearly had very significant pain but still struggled to articulate it;
20

21
22 *“Indescribable to me, I couldn’t, as I sit here I can’t describe it... I had severe
23 pain and it was; I don’t know how you break it down into words”. (P19)*
24
25

26 Knowing “something is wrong” 27

28 Frequently participants had a “gut feeling” that there was something wrong or a
29 strong emotional response to their symptoms;
30
31

32
33 *“You know, I could sort of feel that there was something wrong”, (P2).*
34

35 *“And I thought I can’t do this, I got to get ‘elp, and that’s when I dialled 999...
36 and, you know, everything was going wrong, and I just couldn’t figure out”.
37 (P3).*
38
39

40 A “sense of doom” is often associated with the presentation of MI, but in this group
41 only a few participants reported a strong sense of impending death;
42
43
44

45 *“I felt as if I was going to die (anxious voice)”. (P6)*
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Discussion

We found that patients with DM who experienced an MI exhibited a wide range of symptoms from very classical presentations to very mild symptoms.²³ Patients often were unclear what caused their symptoms.⁴⁷ This diagnostic confusion or uncertainty appears periodically to have been mirrored by clinicians.^{9 24}

The symptoms experienced in this group ranged from those that may be expected by health care professionals, to more atypical symptoms with patients using unusual descriptive terms. The variation in experiences highlights the difficulty for both patients and healthcare providers to correctly attribute these symptoms to a cardiac event.

Patients with DM will often have other significant co-morbidities which can be attributed to their symptoms e.g. breathlessness from chronic obstructive pulmonary disease (COPD) rather than an MI. However, there seems to be an important area of confusion from symptoms related to DM and its control, that can lead to a misattribution of pain symptoms away from a new onset MI. A specific issue among this group is the impact of MI symptoms which were perceived as a side effect of medication (particularly insulin and oral hypoglycaemics). Interpreting episodes of hypoglycaemia and sudden onset MI seems to be particularly challenging with an overlap of many similar symptoms and their sudden onset.²⁵

We found participants had a lack of knowledge of MI symptoms, were falsely reassured by the lack of severe pain or did not conceptualise their milder chest discomfort as chest pain. These factors may all lead to denial or confusion and therefore delay in seeking care.³³ Delay in seeking medical attention during an MI, will have significant prognostic implications.

As the participants' symptoms did not fit with their preconceived ideas of an MI,²⁵ they ascribed it to other less serious causes, or importantly attributed their symptoms to their DM, medication side effects or "hypos"; which is a novel and important finding. The attenuated chest pain competing with other, perhaps more distressing symptoms and so being "crowded out" from the illness cognition of a possible MI, has not been previously reported.

Strengths

Within this study we have reported contemporaneous symptoms from a well described patient group, who can be characterised by their MI diagnosis. We have captured a wide range of participants with MI, by using biochemical confirmation of diagnosis wherever possible, but also by including clinical diagnoses (e.g. for cardiac arrests). Unusually for a qualitative study we have a relatively large number of participants, who were interviewed as early as possible (or allowed to) after the event to reduce recall bias.⁴⁸

Limitations

Despite recruiting participants on the basis of their MI diagnosis, but not specifically on chest pain presentations, participants are likely to have initially volunteered chest pain symptoms to get admitted to a coronary care unit. Markedly discrepant MI narratives are less likely to be represented in this study, as are silent MIs, as they are more likely to go unrecognised and present late. Survivor bias is also a distinct possibility.²¹ While a study size of 39 is good for qualitative research,⁴⁸ it is small in comparison with epidemiological studies so this methodology is therefore unlikely to pick up rarer presentations of MI.

Recruiting on the basis of being able to converse in English will exclude the linguistic nuance of other languages and cultures; important when south Asian populations among others, have a high risk of DM and coronary heart disease. However, we did successfully capture many patients who had English as second language. Additionally the UK NHS struggles to provide reliable, accessible translation; particularly in the acute and out of hours setting, so our findings may more faithfully reflect the real world setting of these decisions and presentations.

Truncating these interviews into quotes also runs the danger of falsely dichotomising symptoms into “typical” and “atypical”. When the transcripts are read in full and in context, a more rounded picture of the event develops. This nuanced view is probably a key element that helps experienced clinicians successfully identify a potential MI, in this group of patients.

How this fits into existing literature

The findings of our study link with previous work within a broad context of psychological models of illness behaviour such as health belief models.⁴⁹ We have used our findings to adapt Rosenstock and Kirsch's health belief model⁴⁹ (see figure 1) so that the impact of DM can modify the steps in the model such as reduced pain from neuropathy during an MI reducing the likelihood of action.

Diagram here (figure 1)

The language of describing pain and particularly the difficulty of describing pain recurs within our sample. Scarry describes this as the "inexpressibility of pain"⁵⁰ and this is seen with some respondents. Others use metaphor and simile to circumvent this issue, which may be helpful to the patient but means a clinician might cognitively process such symptom descriptions as "atypical" or "non cardiac", leading to misdiagnosis and delays in treatment. The term "chest pain" is also problematic³⁸; many of these participants did not conceptualise their chest symptoms as pain and so, Miller has suggested using the term "chest sensation" instead.⁵¹

Our findings have some similarities to other studies about patients' experiences of MI.^{23 24 25 26} The similarity of symptom presentation raises the possibility that these studies are just capturing the heterogeneous array of MI symptoms and this is unlinked to any underlying physiological or pathological process such as gender or DM. However, our finding of patient misattribution of MI symptoms to DM and diabetic medication, in a group at high risk of MI, does have significant clinical implications for patients and clinicians.

Implications for further research

Despite knowing that people with DM are at much higher risk of coronary events we fail to inform patients in the UK about their increased cardio-vascular risk nor identify early those who may be developing such problems. Whether screening people with diabetes for ischaemic heart disease would be beneficial remains a key question. Possibilities include trialling patient education about their CHD risk and its

1
2
3 presentation in the UK Quality and Outcome (QOF) DM check or including this
4 information within DESMOND (desmond-project.org.uk)/DAFNE (www.dafne.uk.com)
5 patient education programmes, but there would be considerable difficulty in
6 designing an educational package that could reliably help patients distinguish
7 between these two aetiological possibilities of “hypo” versus MI.
8
9

10 Implications for practice

11
12 This study could contribute towards increased awareness of MI in those with DM.
13 Patients with DM should be made aware of their increased risk of cardiac events,
14 how they present and how they differ from medication side effects and “hypos”.
15 Clinicians should carefully explore patients with diabetes and their symptoms as well
16 as their interpretation of their symptoms.
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23 a. Contributorship statement

24 All 3 authors fulfil all three of the ICMJE guidelines for authorship, MJ had the
25 original study conception and design and then supervised NB during her iBSc
26 project. NB collected all the data. NB and DDC analysed the final data set. MJ
27 wrote the final manuscript with substantial intellectual input from NB and DDC.
28 All authors approved the final manuscript.
29
30
31
32

33 b. Competing interests

34 None
35

36 c. Funding

37 Royal College of General Practitioners’ Scientific foundation board (grant SFB
38 2011-25). The original project was part of the UCL iBSc in primary health care
39 and formed NB’s dissertation, supervised by MJ.
40
41
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43

44 d. Data sharing statement

45 No additional data are available as participants only consented to quotes
46 being published.
47
48

49 Figure legend

50
51 Figure 1: How diabetes (grey boxes) might affect the “Health Belief model” during
52 MI
53
54

55 With permission from Fig 1. page 115 (adapted) from Victor J. Strecher and Irwin
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Figure 1: How diabetes (grey boxes) might affect the "Health Belief model" during MI
 With permission from Fig 1, page 115 (adapted) from Victor J. Strecher and Irwin M. Rosenstock, "The health belief model", Andrew Baum, Stanton Newman, John Weinmar, Robert West, Chris McManus (eds.), (1997), "Cambridge Handbook of Psychology, Health and Medicine, 9780521436861, Cambridge : Cambridge University

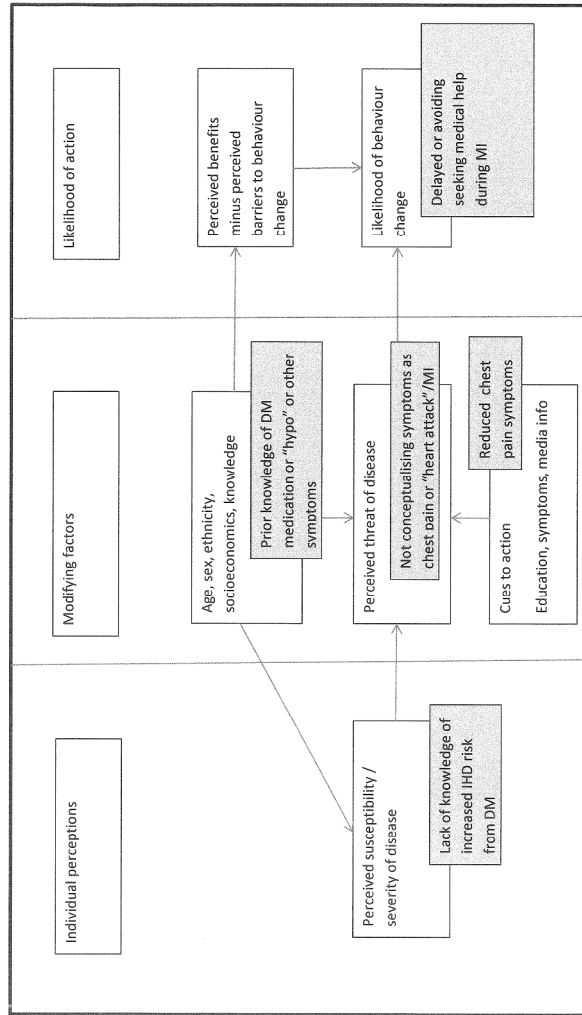


Figure 1- How diabetes (grey boxes) might effect the health belief model during MI

296x419mm (300 x 300 DPI)

	Item	Guide questions/description	Author completed	Location
Domain 1: Research team and reflexivity				
Personal Characteristics				
1	Interviewer/ facilitator	Which author/s conducted the interview or focus group?	NB	See Methods p6
2	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	MD MSc (MJ) undergraduate (NB), BSc (DDC)	Online submission details
3	Occupation	What was their occupation at the time of the study?	Sen Lect (MJ), MB BS / iBSc student (NB), student/junior doc (DDC)	Cover sheet p1
4	Gender	Was the researcher male or female?	Both genders	
5	Experience and training	What experience or training did the researcher have?	MJ extensive research and research supervision, NK / DDC developed expertise during study	
Relationship with participants				
6	Relationship established	Was a relationship established prior to study commencement?	no	
7	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	Information as set out in pt info leaflet as agreed by IRC/ ethics committee	Methods section p6
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	NK identified as medical student, MJ as academic and clinician	Patient information sheet (PIS) available on request

1	Domain 2: study design				
2					
3	Theoretical framework				
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9	9	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	Thematic analysis (Ritchie and Spencer)	Methods section p 6-7
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17	Participant selection				
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20	10	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>	Pragmatic sample	Methods section p 6-7
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28	11	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>	Prior selection by clinical team (to establish well enough to participate), approach with PIS by researcher, and "cooling off" period	Methods section p 6-7
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35	12	Sample size	How many participants were in the study?	43, 39 analysed	Results section p9
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41	13	Non-participation	How many people refused to participate or dropped out? Reasons?	Not recorded	
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46	Setting				
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48	14	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	On hospital ward (including coronary care unit)	Methods section p6-7
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53	15	Presence of non-participants	Was anyone else present besides the participants and researchers?	Occasionally patients' relatives stayed during the interview.	
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16	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>		Recorded in table 1 of manuscript
Data collection				
17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Yes	Methods section p6-7
18	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No	Methods section p6-7
19	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio-recording	Methods section p6-7
20	Field notes	Were field notes made during and/or after the interview or focus group?	Yes	Methods section p6-7
21	Duration	What was the duration of the interviews or focus group?	5-48 minutes	Results section p9
22	Data saturation	Was data saturation discussed?	Yes	Results p10
23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No as no identifiable data was removed from the ward	See methods p6-7
Domain 3: analysis and findings				
Data analysis				
24	Number of data coders	How many data coders coded the data?	2	
25	Description of the coding tree	Did authors provide a description of the coding tree?	Thematic analysis was recorded as an excel spreadsheet not a tree	

26	Derivation of themes	Were themes identified in advance or derived from the data?	Data derived	See methods p6-7
27	Software	What software, if applicable, was used to manage the data?	Spreadsheet and word processing software	See methods p8
28	Participant checking	Did participants provide feedback on the findings?	No (see previous comments)	See methods p6
Reporting				
29	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>	Yes identified by participant number.	See methods p7
30	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes	
31	Clarity of major themes	Were major themes clearly presented in the findings?	Yes	See results p9-18
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes	See results p9-18

BMJ Open

“Just like a normal pain”- what do people with diabetes mellitus experience when having a myocardial infarction - a qualitative study recruited from UK hospitals.

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2016-015736.R2
Article Type:	Research
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Primary Subject Heading:	Cardiovascular medicine
Secondary Subject Heading:	Diabetes and endocrinology, Qualitative research, Emergency medicine, General practice / Family practice
Keywords:	Chest pain, Myocardial infarction < CARDIOLOGY, Diabetic nephropathy & vascular disease < DIABETES & ENDOCRINOLOGY

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7 “Just like a normal pain”- what do people with diabetes mellitus
8 experience when having a myocardial infarction - a qualitative study
9 recruited from UK hospitals.
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Abstract

Objective: The objective of the study was to investigate the symptoms people with diabetes experience when having a myocardial infarction (MI), their illness narrative, and how they present their symptoms to the health service.

Setting: Three London (United Kingdom) hospitals- Coronary care units (CCU) and medical wards.

Participants: Patients were recruited with diabetes mellitus (DM) (Type 1 & 2) with a clinical presentation of MI (ST elevated myocardial infarction [STEMI], non ST elevated myocardial infarction [NSTEMI], acute MI unspecified & cardiac arrest). 43 participants were recruited, 39 interviews met the study criteria and were analysed. They were predominantly male (n=30), aged 40-90 years and white British (18/39), just over a half were from other ethnic groups. The majority had type II DM (n=35); 24 had an NSTEMI, 10 had an STEMI and 5 had other cardiac events.

Definitions of selection / exclusion criteria: a diagnosis of MI, and DM, the ability to communicate enough English to complete the interview. Ward staff made a clinical judgement that the participant was post-treatment, clinically stable and well enough to participate.

Methods: A qualitative study utilising taped and transcribed interviews analysed using a thematic analysis.

Results: While most participants did experience chest pain, it was often not their most striking symptom. As their chest pain did not match their expectations of what a "heart attack" should be, participants developed narratives to explain these symptoms, including the symptoms being effects of their DM ("hypos"), side effects of medication (oral hypoglycaemics) or symptoms (such as breathlessness and indigestion) related to other comorbidities; often leading to delays in seeking care.

Conclusions:

While truly absent chest pain during MI among people with DM was rare in this study, patients' attenuated symptoms often led to delay in seeking attention, and this may result in delays in receiving treatment.

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3 **Data sharing:** - No additional data available.
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6 **Article summary**
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8 Strengths and weaknesses
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11 This is a study of people with diabetes experiencing an MI.
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13 Strengths of the study include:
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- 15 • contemporaneous patients' descriptions of their symptoms and illness
16 narrative just after an MI,
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- 18 • a model of how attenuated MI symptoms might alter help seeking behaviour,
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- 20 • the participants were from a wide demographic background in terms of age,
21 ethnicity and disease burden.
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24 Weaknesses include:
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- 26 • by recruiting patients from coronary care units we will not have captured
27 markedly discrepant presentations,
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- 29 • by recruiting on the basis of the ability to communicate in English we will have
30 lost some cultural and linguistic nuance in symptom presentation.
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Background

Diabetes Mellitus (DM) is a common health problem worldwide and affects 4-6% of the UK population.¹ Cardiovascular disease (CVD) is the major life threatening complication of DM in the UK.^{2 3 4} Myocardial infarction (MI) is the prime cause of excess mortality among those with DM, with a 3-fold increased risk of coronary heart disease (CHD) mortality,^{5 6} a 6-fold increased risk of myocardial infarction (MI)⁷ and a worse prognosis from MI compared with populations without diabetes.⁸

Possible mechanisms of this excess mortality risk include comorbidities such as hypertension, dyslipidaemia and chronic kidney disease. An important element in this observed increased mortality may be late or missed presentation by patients, and diagnosis by clinicians.^{9 10 11}

Up to a third of people who suffer an MI can have no chest pain; however people with DM make up a larger proportion of this group (32.6% vs 25.4% in one study).¹² However, when people with DM do have symptoms of an MI, their symptoms may often be atypical¹³ or unusual.¹⁴ Nevertheless, there is conflicting evidence around this issue: Funk found no statistically significant difference in CHD symptom presentation in people with and without DM, but did report non-significant increases in dyspnoea, neck and throat pain among those with DM.¹⁵ Kentsch found no differences between these groups in the frequency or severity of chest pain but also identified differences in the prevalence of dyspnoea.¹⁶ One review found conflicting results about differing MI symptoms among women with and without DM.¹⁷

There are several methodological reasons why these studies may have conflicting results: being underpowered,^{18 19} being unrepresentative of the population at risk,¹⁸ or recruited from highly selected hospital populations.²⁰ Survivor bias (i.e. living to tell the tale of your symptoms) may also be an important issue in a condition such as MI which has a high early mortality.²¹

There is a biological basis for altered perception of pain among people with diabetes in that cardiac autonomic neuropathy (CAN) is a complication of DM and leads to

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3 altered pain perception, meaning a patient might not experience pain caused by
4 myocardial ischaemia.²⁰
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7 Several qualitative studies have explored patients' symptoms during MI.^{22 23 24 25 26}

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9 ¹⁸ Within the general population experiencing MI, there are several issues identified
10 including; the considerable psychological impact of pain and specifically cardiac
11 pain,²⁷ cardiac symptoms that can be interpreted as pain, but also can trigger
12 symptoms such as anxiety (both as a trigger and barrier to action) and fear,²⁸
13 producing responses like uncertainty,²⁹ and denial.³⁰ Further factors identified
14 include patients not recognising their symptoms as MI, experiencing vague
15 symptoms,³¹ misattributing their symptoms,^{23 24} erroneous expectations of an MI,
16 ³¹ and the decisions patients make during their MI.³² Other factors include delays in
17 seeking care.^{30 11} Theoretical models of delay in seeking treatment specifically in
18 relation to MI have been summarised by Dracup.³³ Underestimating personal risk of
19 an MI,²³ and perceived lack of vulnerability to heart disease link to the concept of
20 "lay epidemiology" and of "coronary candidacy" i.e. not fitting assumptions about the
21 sort of person who gets a heart attack.³⁴
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31 There is a role of gender with MI symptoms and its interpretation; work exploring
32 women's experience of MI symptoms found that women with diabetes had more
33 atypical and painless MIs than men.³⁵ In studies of denial among men, there has
34 been exploration of the impact of their gender roles adversely effecting health
35 seeking behaviour.³⁶
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40 In studies specifically exploring the experience of patient with diabetes and MI, many
41 similar themes emerge. However Angerud finds a variability in the experience of MI
42 symptoms while exploring the patients' response to symptoms, perceived
43 susceptibility, and symptom interpretation (but found that MI symptoms were rarely
44 ascribed to DM).²⁵ Other studies in this population also identify breathlessness as a
45 presenting symptom, misinterpretation of symptoms; and their diabetes influencing
46 patients' decision making during events.³⁷
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53 Clinician factors
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3 The way clinicians ask about chest symptoms may be problematic. Clinicians ask
4 about “chest pain”, however the term “pain”,^{38 39} is often not used by patients
5 experiencing MI.
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9 In the current study, we aimed to address some of the limitations of previous
10 research by recruiting only DM patients with clear evidence of a recent MI,
11 regardless of their chest pain presentation, and use of a qualitative methodology to
12 explore how these patients describe their symptoms. Qualitative methods can help
13 overcome a narrow clinician focus and help develop a patient orientated view when
14 exploring symptoms of disease.^{37 40 23 41} The aim of the study was to investigate
15 the symptoms people with diabetes experience when having a myocardial infarction,
16 their illness narrative, and how they present their symptoms to the health service.
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Methods

This was a qualitative study where interviews were undertaken with patients with DM who have recently had a confirmed MI, recruited within coronary care units (CCU). Eligibility criteria included a confirmed diagnosis of MI (according to AHA criteria ⁴²), a clinical diagnosis of DM and the ability to communicate (understand and speak) enough English to complete the interview. Clinical staff identified participants and ensured they were post-treatment, clinically stable and well enough to participate. This subjective judgement was made by the clinical staff involved in participants' care as required by the ethics committee. Participants were approached as soon as possible after the diagnosis by a researcher (NB) so we could be sure that they had had an MI (usually a retrospective or working diagnosis) and to minimise recall bias about symptoms. Once invited, they were given a patient information sheet (PIS) about the study and 24 hours to decide whether to participate (see comments regarding ethics approval). The interviews took place in three London, UK hospitals. We aimed to recruit consecutive patients (but this proved unworkable) so this was a pragmatic sample. ⁴³

The interviews were semi-structured and iterative building from a topic guide to include a narrative of the course, range, character and severity of the symptoms the person experienced before and during their MI. We used a checklist of AMI symptoms based on Funk's acute myocardial infarction (AMI) symptom list. ¹⁵ This is distinct to Diamond and Forrester's classification of angina typicality. ⁴⁴ The checklist was worked through to ensure symptoms were absent and not just omitted. Ideas about expected symptoms of an MI, and symptom attribution were also explored as people often develop complex narratives about their illnesses. ⁴⁵ We also explored participants' thoughts about their illness, treatments they had attempted, motives and triggers for seeking help, awareness and knowledge of the symptoms of a heart attack.

Interviews were audio recorded, field notes and baseline patient information were noted. Details gathered included the type of MI (ECG changes, troponin level, clinical assessment), the patients' demographics, co-morbidities (type and duration of DM,

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3 other disease), risk factors, family history, medication use and information that might
4 impact on symptom perception, from the informant and their medical records. All
5 participants were allocated a code number to link their data together and then
6 anonymised (apart from the consent form) so that identifiable data did not leave the
7 ward setting.
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12 The audio taped interviews were transcribed verbatim and manually analysed using
13 a thematic framework approach,^{22 46} using word processing and spreadsheet
14 software. Agreement was specifically sought between reviewers about the
15 classification of symptoms as either typical or atypical as outlined by Funk.¹⁵ Two
16 independent researchers (NB, DDC) read the transcripts and analysed the data
17 using the following steps: familiarisation, identifying a thematic framework, indexing,
18 charting, mapping and interpretation. Throughout this process, transcripts were
19 repeatedly re-read to focus on specific points and ideas, to verify the presence of the
20 themes and sub-themes that are identified and ensure the context of the themes has
21 been preserved. There was then a dialogue between all the researchers which was
22 reflexive in nature linking the findings back to the study's aims. The analysis was
23 deductive or theoretical in approach in that we were looking for themes around
24 diabetes and myocardial infarction, and bounded by an expectation of probable
25 reduced or absent pain symptomatology and this shaped our topic guide and
26 approach to the data. However, the analysis was also inductive in nature, in that we
27 needed to derive themes from the data, in as much that if there were no pain
28 symptoms during the MI, we needed the participants and their narratives to tell us
29 what they did experience. The themes around reporting of symptoms is semantic
30 (or a surface meaning) in that we are largely reporting the participants' descriptions
31 of their experience. However, the explanatory models around what participants
32 thought caused their symptoms and reactions to those symptom is a much more
33 latent thematic or interpretive analysis.²² Representative quotes (with consent)
34 were used and have identifying details to link the theme to the participants'
35 characteristics.
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53 The lay term "heart attack" is used extensively in the transcripts; this can have a
54 broad popular meaning but we will assume is used by participants to suggest a
55 myocardial infarction.
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2
3 Ethical approval for this study and the use of quotes was obtained from the
4 Hertfordshire Research Ethics Committee. (Project no: 11/EE/0045). The committee
5 requested that we allowed a “cool off” period of 24 hours from approach to obtaining
6 consent. Data protection and local hospital trust R&D policies were followed.
7
8 Consent was not originally sought to disclose the full interview transcripts.
9
10

11 Patient involvement

12
13
14 The original idea for this study was based on a clinical encounter in general practice.
15 A patient consulted MJ his GP, having suffered a severe MI despite having minimal
16 symptoms and subsequently developed severe heart failure. Before his death, this
17 patient agreed to support research in this area and filmed a brief video of his
18 experiences. A broader study (with same research question but a different
19 methodology) on this field was presented and supported by the North East London
20 Diabetes Research Network Lay Panel Meeting in 2011. Patients’ narratives
21 constitute the data underlying this study.
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Results

Forty three participants were recruited from the participating hospitals, however 4 interviews proved unusable due to not meeting study recruitment criteria on detailed case review and were excluded, resulting in a total of 39 participants' data available for analysis. The interviews had a mean duration of 20mins 33 sec (with a range of 5 mins 14 secs to 48mins 46 secs) and were all undertaken by one interviewer; NB. The study comprised of 30 men and 9 women; with an age range of 40-90, 35 participants had type 2 DM and 4 had type 1 DM. All participants had confirmed acute coronary syndrome; 24 had NSTEMIs, 10 had STEMIs and 5 had other MIs (acute MI-unspecified including 4 cardiac arrests). Their ethnic categories were White British (n=18), Asian/ south Asian (n=7), African or Afro-Caribbean (n=3) and others (n=5) e.g. Turkish, Maltese etc. A number (n=6) declined to state their ethnicity or instead identified their religious affiliation e.g. "Church of England", "Jewish" etc. One interview was done via an informal family translator but frequently family members would participate in the interview, clarifying the order of events or reminding the participant about elements of their illness narrative (which may have been clouded by their illness including cardiac arrest or treatment such as strong opioid analgesics). Participants were usually approached to participate the day following admission, or the Monday following a weekend admission and then interviewed usually the following day after consenting to participate as per our ethics approval. Data saturation was achieved. Each participant was given a study number between 1 to 43 and quotes are linked e.g. participant 22 (P22)

Themes

The analysis of the data led to the identification of the following themes and sub themes.

Symptoms

- Typical vs atypical presentations
 - Atypical presentations
- Absence of pain

Attribution and consequences

- Attributing symptoms to co-morbidities
 - Ascribing symptoms to DM
 - Ascribing symptoms to hypoglycaemia
- Delay in seeking help
- Gradual onset of symptoms
 - Multiple symptoms
- Lack of awareness of MI symptoms or their increased risk of MI
 - Experience of repeat MIs
- Language of pain
- Knowing “something was wrong”

However, these themes are not distinct. The nature of obtaining patients’ narratives means that there are complex, inseparable relationships in concepts and ideas, with a continuum across themes and subthemes.

Symptoms

1
2
3 Participants described a wide range of symptoms, primarily around chest pain and
4 discomfort. However, other symptoms associated with MI such as sweating and
5 breathlessness were described, as well as a series of symptoms that are not usually
6 associated with MI presentations. With regard to chest pain, we found a range of
7 symptom presentations.
8
9

10 11 Typical versus atypical presentations.

12
13 Chest pain of a specific character is regarded as the classic symptom of MI and was
14 present in most of these interviews;
15
16

17
18 *“It was like your chest was being crushed.” (P3)*
19

20
21 Many of these descriptions catch this essence of a typical MI;
22

23
24 *“Err a real dull ache and like someone is screwing up, like a tight chest just
25 really tight, like someone is squeezing it inside....yeah like a really, really dull
26 pain”... “it started hurting and made me feel really ill ...but then I went really
27 pale & started sweating .. absolutely saturated.. just a really tight chest and
28 sore like, as if there was a weight directly on top of me”. (P 11)*
29
30
31

32
33 Most of those in the study experienced some typical symptoms. However, typical
34 symptoms with a recent chronology (necessary to suspect MI) was not always
35 present or immediately apparent in the interviews.
36
37

38
39 Some experienced sweating; regarded as a typical MI symptom;
40

41
42 *“My night clothes were soaking wet.” (P3).*
43

44
45 Breathlessness was also experienced either with pain or separately, which although
46 classed as a “typical” symptom [23], is not generally recognised by clinicians to be
47 suggestive of an MI;
48

49
50 *“I can’t breathe, you couldn’t breathe, my wife she phone a medic ... No you
51 got the pain and you can’t breathe...you think you’re gonna die for the lack of
52 breath”, (P14)*
53

54
55 *“Like somebody’s pushing me...and I’m short of breath and then it was getting
56 worse and it start burning”. (P35)*
57
58
59
60

Atypical pain

Some of those in this study sometimes narrated their experience of a diffuse and ambiguous set of symptoms that may not raise suspicion of MI;

"It feels like something crawling up my arm... and it bites deep in there...the only way I can describe it, it feels like someone is in there with claws and they're tearing at your inside. Just screaming and pulling at it. Very, very strange pain indeed", (P24)

although this person later describes quite typical sounding symptoms. Others described the quality of their pain;

"It was just sticking pain, it was just a really pain, stay there for about 3 hours", (P30)

"Like a normal pain, it wasn't a pain, actually it was dull". (P26)

These quotes raise the issue of participants' use of language which is discussed later.

The following quote illustrates a mixture of some typical and atypical symptoms;

"I can feel something happening you know, my chest, had very bad pain in my arm, my neck and my leg, I couldn't move... Yeah sharp pain, very sharp ...Somebody was pressing my, you know, chest...My back... All the way up to the waist...I couldn't breathe you know. I get very deep breath, I tried to do it but it didn't go, somebody was choking me". (P5)

The inseparability of these two types of symptoms (typical/ atypical) is raised in the discussion.

Symptoms of weakness and tiredness were also reported around the timing of the MI. One participant could not walk and said;

"It's just the sheer um lethargy really, I just couldn't do anything...I wasn't giddy and I wasn't in a lot of pain, I just couldn't sort of come to, I was, I couldn't put one foot in front of the other. I was just so weak". (P10)

Absence of pain

1
2
3 Some clearly stated they had no chest pain;

4
5 *“Nothing, nothing, no discomfort, no pain” (pre cardiac arrest), (P27)*

6
7
8 but this participant did have pain after being resuscitated. Another reported;

9
10 *“No pain, no sweating, nothing else” (pre cardiac arrest). (P23)*

11
12 Both of these participants experienced cardiac arrests, so some degree of event
13 amnesia cannot be excluded.

14 15 16 17 Attribution and consequences

18 19 Attributing symptoms to co-morbidities

20
21 The participants seemed to rationalise their symptoms and find a reason to dismiss
22 that the cause of their symptoms could be a “heart attack”. Many attributed their
23 symptoms to other illness and causes. Most commonly, they attributed their
24 symptoms to other illness and causes. Most commonly, they attributed their
25 symptoms to indigestion leading to self-medication with antacids for this;

26
27
28
29 *“when you feel bloated and gassy and it’s similar to that sort of pain. That’s*
30 *why I mistook it for being indigestion.... I put it down to nerves or exercise*
31 *...but then in the early hours of Sunday morning I realised it couldn’t have*
32 *been indigestion because it was paining me a great deal”, (P31)*

33
34
35
36
37 *“I took, bicarb of soda, didn’t work. I took um Gaviscon (antacid remedy),*
38 *didn’t work. The antibiotics didn’t work. That’s when I knew, there was more to*
39 *this”. (P3)*

40
41
42 but symptoms were also attributed to other causes that included asthma, muscular
43 aches, panic attacks, stress and importantly in this group, their DM;

44
45
46
47 *“Because of, I have other illness(es), like blood pressure, diabetes, I didn’t think*
48 *(of MI), because I thought there is nothing wrong with my heart.” (P4).*

49
50 These quotes also link to the theme of delay (both by patient and clinician in this
51 instance) which is discussed further on.

52 53 54 55 Ascribing symptoms to DM

1
2
3 Participants sometimes specifically attributed their symptoms to (lack) of control of
4 their DM, symptoms of DM or side effects of their medication;
5
6

7 *"I didn't realise I was having heart attack, so I was feeling rotten ...I was*
8 *hungry. Well I wasn't really hungry but I know, don't, diabetic, ...that's when*
9 *the pain come, and I went to bed and it woke me up around 2 in the morning",*
10 *(P17)*
11
12

13
14 *"Well dizzy, tired, again I'm dizzy all the time with diabetes, you get that, that's*
15 *part and parcel of being diabetic". (P17)*
16
17

18
19 Participant 3 also attributed her dizziness during her MI to her DM;
20

21 *"Not fainting, but you know dizzy turns, because I do get these dizzy turns.*
22 *You see, this is all in with the diabetes you see". (P3)*
23
24

25 Ascribing symptoms to hypoglycaemia

26

27
28 Patients when experiencing some symptoms, particularly sweating and feeling
29 unwell perceived themselves to be experiencing hypoglycaemia ("Hypo"), for
30 example;
31
32

33 *"because I am diabetic, right, um, I thought, initially I thought it was um low*
34 *blood sugar", (P2.)*
35
36

37 *"A little (of sweating) bit, but ...I didn't have my testing gear with me & I*
38 *thought that it might be a hypo at the time". (P11)*
39
40

41
42 Participant 3 perceived herself to be experiencing hypoglycaemia;
43

44 *"That's when I knew, there was more to this (symptoms) and I had, I don't*
45 *know whether I had five hypo's in that week, but I was rolling all over the*
46 *place". (P3).*
47
48

49 Delay in seeking help

50

51
52 Delay in help seeking was a prominent feature in these narratives;
53
54

55 *"I think to be honest it (chest pain) came on suddenly but I tended to ignore it,*
56 *I've got one more screw to put in", (P21)*
57
58
59
60

1
2
3 *"I waited till my GP opened in the morning. I called him and I told him what's*
4 *wrong, they said 'just phone the ambulance' ". (P5).*
5
6

7 This delay could be ascribed to participants' failure to attribute symptoms to MI,
8 attribution to co-morbidities, lack of symptom awareness or lack of awareness of
9 increased risk of MI; but participants often realised that something more serious was
10 occurring when their symptoms did not improve;
11
12

13
14 *"But it was there too long, so I said 'could be heart attack' ". (P30)*
15

16
17 Often participants had dismissed or explained away these one off or minor
18 symptoms and did not think much of them, except with hindsight;
19

20
21 *"more during the week. Nothing sharp... it was just a niggling thing, it just*
22 *came and then it went away ... you just didn't think too much of any of these*
23 *factors in isolation; but together". (P31)*
24
25

26
27 With others, denial was behind their delay;
28

29 *"Well I thought it was a heart attack but I didn't really want to admit it at the*
30 *time. Anything other than a heart attack". (P17)*
31
32

33 34 35 36 Gradual onset of symptoms

37
38 For some participants part of this delay was the gradual rather than sudden onset of
39 symptoms;
40
41

42 *"Well no ...it had happened a fortnight before"... "Sat in the chair for about*
43 *20mins and then it went so then I said to my wife, I told her 'If it happens*
44 *again I would be calling the doctor' ". (P20)*
45
46
47

48 Multiple symptoms

49
50 The respondents often had complex narratives where chest pain was a part of the
51 symptom complex they described, but their chest pain symptom may not have been
52 the most prominent, important or distressing feature; exemplified by the following
53 quote;
54
55
56
57
58
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60

1
2
3 *"It (chest pain) did come on suddenly ...at the same time I had this very heavy*
4 *perspiration...& this very uncomfortable tummy ache...Err all three things*
5 *hitting me at once; you don't pick one out in particular ...all those three factors*
6 *the er tummy ache the excessive err sweating and the pain in the chest um I*
7 *could point to one and say look that was the main problem.. they were all a*
8 *problem at that short period of time". (P 25)*
9
10
11
12

13 14 15 16 Lack of awareness of MI symptoms or their increased risk of MI

17
18 Many of these respondents, despite having long standing diabetes, previous cardiac
19 events or a strong family history, seemed unaware that they were at a high risk of
20 subsequent MI;
21
22

23
24
25 *"I thought ...how can I have a heart attack? Right. But you see, this might be*
26 *relevant as well; both my side of my family, my mother's side and my father's*
27 *side are diabetic. My father had a heart attack as well and he died from it. My*
28 *mother had a triple heart bypass. My elder brother's had an angioplasty, right,*
29 *so it does run in the family" (P2)*
30
31
32

33 34 Experiences of a repeat MI

35
36 Participants who had previous MIs might be expected to have a good working
37 knowledge of these symptoms and respond accordingly if it recurred. We found
38 however that often they did not do so;
39
40

41
42 *"I should have guessed, right, um, it's exactly the same symptoms as when I*
43 *had my first heart attack". (P2)*
44
45

46 Language of pain

47
48 The expectation of severe chest pain is key to many patients' and doctors' model of
49 what an MI should be like and is apparent in some of the previous themes. However,
50 many of these respondents had symptoms that they didn't feel reached a threshold
51 of severity that they would call "pain";
52
53
54

55
56 *"I suppose people would call it a pain, I don't know, I wouldn't, I would still call*
57 *it severe discomfort...dull, rather than, no it wasn't sharp.... I won't put it (pain*
58
59
60

1
2
3 severity score) higher, otherwise I probably would have called an ambulance
4 straight away”, (P20)
5
6

7 “No, it was a constant. When I say pain, ache, it wasn’t a pain that was
8 making me double up or anything”. (P25)
9

10
11 While some struggled to conceptualise their symptoms as pain, others struggled to
12 use words to describe their symptoms;
13

14
15 *“It’s so difficult cos it was more uncomfortable than a pain that you can
16 describe ... I don’t know how to describe it”. (P20)*
17
18

19 While others clearly had very significant pain but still struggled to articulate it;
20

21
22 *“Indescribable to me, I couldn’t, as I sit here I can’t describe it... I had severe
23 pain and it was; I don’t know how you break it down into words”. (P19)*
24
25

26 Knowing “something is wrong”

27

28 Frequently participants had a “gut feeling” that there was something wrong or a
29 strong emotional response to their symptoms;
30
31

32
33 *“You know, I could sort of feel that there was something wrong”, (P2).*
34

35 *“And I thought I can’t do this, I got to get ‘elp, and that’s when I dialled 999...
36 and, you know, everything was going wrong, and I just couldn’t figure out”.
37 (P3).*
38
39

40 A “sense of doom” is often associated with the presentation of MI, but in this group
41 only a few participants reported a strong sense of impending death;
42
43
44

45 *“I felt as if I was going to die (anxious voice)”. (P6)*
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Discussion

We found that patients with DM who experienced an MI exhibited a wide range of symptoms from very classical presentations to very mild symptoms.²³ Patients often were unclear what caused their symptoms.⁴⁷ This diagnostic confusion or uncertainty appears periodically to have been mirrored by clinicians.^{9 24}

The symptoms experienced in this group ranged from those that may be expected by health care professionals, to more atypical symptoms with patients using unusual descriptive terms. The variation in experiences highlights the difficulty for both patients and healthcare providers to correctly attribute these symptoms to a cardiac event.

Patients with DM will often have other significant co-morbidities which can be attributed to their symptoms e.g. breathlessness from chronic obstructive pulmonary disease (COPD) rather than an MI. However, there seems to be an important area of confusion from symptoms related to DM and its control, that can lead to a misattribution of pain symptoms away from a new onset MI. A specific issue among this group is the impact of MI symptoms which were perceived as a side effect of medication (particularly insulin and oral hypoglycaemics). Interpreting episodes of hypoglycaemia and sudden onset MI seems to be particularly challenging with an overlap of many similar symptoms and their sudden onset.²⁵

We found participants had a lack of knowledge of MI symptoms, were falsely reassured by the lack of severe pain or did not conceptualise their milder chest discomfort as chest pain. These factors may all lead to denial or confusion and therefore delay in seeking care.³³ Delay in seeking medical attention during an MI, will have significant prognostic implications.

As the participants' symptoms did not fit with their preconceived ideas of an MI,²⁵ they ascribed it to other less serious causes, or importantly attributed their symptoms to their DM, medication side effects or "hypos"; which is a novel and important finding. The attenuated chest pain competing with other, perhaps more distressing symptoms and so being "crowded out" from the illness cognition of a possible MI, has not been previously reported.

Strengths

Within this study we have reported contemporaneous symptoms from a well described patient group, who can be characterised by their MI diagnosis. We have captured a wide range of participants with MI, by using biochemical confirmation of diagnosis wherever possible, but also by including clinical diagnoses (e.g. for cardiac arrests). Unusually for a qualitative study we have a relatively large number of participants, who were interviewed as early as possible (or allowed to) after the event to reduce recall bias.⁴⁸

Limitations

Despite recruiting participants on the basis of their MI diagnosis, but not specifically on chest pain presentations, participants are likely to have initially volunteered chest pain symptoms to get admitted to a coronary care unit. Markedly discrepant MI narratives are less likely to be represented in this study, as are silent MIs, as they are more likely to go unrecognised and present late. Survivor bias is also a distinct possibility.²¹ While a study size of 39 is good for qualitative research,⁴⁸ it is small in comparison with epidemiological studies so this methodology is therefore unlikely to pick up rarer presentations of MI.

Recruiting on the basis of being able to converse in English will exclude the linguistic nuance of other languages and cultures; important when south Asian populations among others, have a high risk of DM and coronary heart disease. However, we did successfully capture many patients who had English as second language. Additionally the UK NHS struggles to provide reliable, accessible translation; particularly in the acute and out of hours setting, so our findings may more faithfully reflect the real world setting of these decisions and presentations.

Truncating these interviews into quotes also runs the danger of falsely dichotomising symptoms into “typical” and “atypical”. When the transcripts are read in full and in context, a more rounded picture of the event develops. This nuanced view is probably a key element that helps experienced clinicians successfully identify a potential MI, in this group of patients.

How this fits into existing literature

The findings of our study link with previous work within a broad context of psychological models of illness behaviour such as health belief models.⁴⁹ We have used our findings to adapt Rosenstock and Kirsch's health belief model⁴⁹ (see figure 1) so that the impact of DM can modify the steps in the model such as reduced pain from neuropathy during an MI reducing the likelihood of action.

Diagram here (figure 1)

The language of describing pain and particularly the difficulty of describing pain recurs within our sample. Scarry describes this as the "inexpressibility of pain"⁵⁰ and this is seen with some respondents. Others use metaphor and simile to circumvent this issue, which may be helpful to the patient but means a clinician might cognitively process such symptom descriptions as "atypical" or "non cardiac", leading to misdiagnosis and delays in treatment. The term "chest pain" is also problematic³⁸; many of these participants did not conceptualise their chest symptoms as pain and so, Miller has suggested using the term "chest sensation" instead.⁵¹

Our findings have some similarities to other studies about patients' experiences of MI.^{23 24 25 26} The similarity of symptom presentation raises the possibility that these studies are just capturing the heterogeneous array of MI symptoms and this is unlinked to any underlying physiological or pathological process such as gender or DM. However, our finding of patient misattribution of MI symptoms to DM and diabetic medication, in a group at high risk of MI, does have significant clinical implications for patients and clinicians.

Implications for further research

Despite knowing that people with DM are at much higher risk of coronary events we fail to inform patients in the UK about their increased cardio-vascular risk nor identify early those who may be developing such problems. Whether screening people with diabetes for ischaemic heart disease would be beneficial remains a key question. Possibilities include trialling patient education about their CHD risk and its

1
2
3 presentation in the UK Quality and Outcome (QOF) DM check or including this
4 information within DESMOND (desmond-project.org.uk)/DAFNE (www.dafne.uk.com)
5 patient education programmes, but there would be considerable difficulty in
6 designing an educational package that could reliably help patients distinguish
7 between these two aetiological possibilities of “hypo” versus MI.
8
9

10 Implications for practice

11
12 This study could contribute towards increased awareness of MI in those with DM.
13 Patients with DM should be made aware of their increased risk of cardiac events,
14 how they present and how they differ from medication side effects and “hypos”.
15 Clinicians should carefully explore patients with diabetes and their symptoms as well
16 as their interpretation of their symptoms.
17
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19
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21
22

23 a. Contributorship statement

24 All 3 authors fulfil all three of the ICMJE guidelines for authorship, MJ had the
25 original study conception and design and then supervised NB during her iBSc
26 project. NB collected all the data. NB and DDC analysed the final data set. MJ
27 wrote the final manuscript with substantial intellectual input from NB and DDC.
28 All authors approved the final manuscript.
29
30
31
32

33 b. Competing interests

34 None
35

36 c. Funding

37 Royal College of General Practitioners’ Scientific foundation board (grant SFB
38 2011-25). The original project was part of the UCL iBSc in primary health care
39 and formed NB’s dissertation, supervised by MJ.
40
41
42
43

44 d. Data sharing statement

45 No additional data are available as participants only consented to quotes
46 being published.
47
48

49 Figure legend

50
51 Figure 1: How diabetes (grey boxes) might affect the “Health Belief model” during
52 MI
53
54

55 With permission from Fig 1. page 115 (adapted) from Victor J. Strecher and Irwin
56 M. Rosenstock, “The health belief model”, Andrew Baum, Stanton Newman, John
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58
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Figure 1: How diabetes (grey boxes) might affect the "Health Belief model" during MI
 With permission from Fig 1, page 115 (adapted) from Victor J. Strecher and Irwin M. Rosenstock, "The health belief model", Andrew Baum, Stanton Newman, John Weinmar, Robert West, Chris McManus (eds.), (1997), "Cambridge Handbook of Psychology, Health and Medicine, 9780521436861, Cambridge : Cambridge University

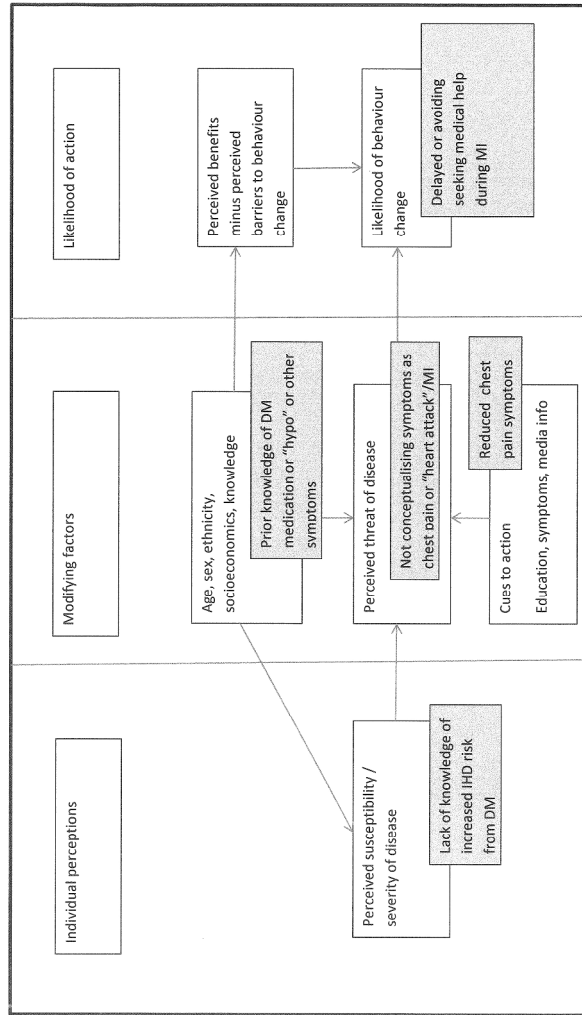


Figure 1- How diabetes (grey boxes) might effect the health belief model during MI

296x419mm (300 x 300 DPI)

	Item	Guide questions/description	Author completed	Location
Domain 1: Research team and reflexivity				
Personal Characteristics				
1	Interviewer/ facilitator	Which author/s conducted the interview or focus group?	NB	See Methods p6
2	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	MD MSc (MJ) undergraduate (NB), BSc (DDC)	Online submission details
3	Occupation	What was their occupation at the time of the study?	Sen Lect (MJ), MB BS / iBSc student (NB), student/junior doc (DDC)	Cover sheet p1
4	Gender	Was the researcher male or female?	Both genders	
5	Experience and training	What experience or training did the researcher have?	MJ extensive research and research supervision, NK / DDC developed expertise during study	
Relationship with participants				
6	Relationship established	Was a relationship established prior to study commencement?	no	
7	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	Information as set out in pt info leaflet as agreed by IRC/ ethics committee	Methods section p6
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	NK identified as medical student, MJ as academic and clinician	Patient information sheet (PIS) available on request

1	Domain 2: study design				
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3	Theoretical framework				
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9	9	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	Thematic analysis (Ritchie and Spencer)	Methods section p 6-7
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17	Participant selection				
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20	10	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>	Pragmatic sample	Methods section p 6-7
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28	11	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>	Prior selection by clinical team (to establish well enough to participate), approach with PIS by researcher, and "cooling off" period	Methods section p 6-7
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35	12	Sample size	How many participants were in the study?	43, 39 analysed	Results section p9
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41	13	Non-participation	How many people refused to participate or dropped out? Reasons?	Not recorded	
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46	Setting				
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48	14	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	On hospital ward (including coronary care unit)	Methods section p6-7
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53	15	Presence of non-participants	Was anyone else present besides the participants and researchers?	Occasionally patients' relatives stayed during the interview.	
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16	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>		Recorded in table 1 of manuscript
Data collection				
17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Yes	Methods section p6-7
18	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No	Methods section p6-7
19	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio-recording	Methods section p6-7
20	Field notes	Were field notes made during and/or after the interview or focus group?	Yes	Methods section p6-7
21	Duration	What was the duration of the interviews or focus group?	5-48 minutes	Results section p9
22	Data saturation	Was data saturation discussed?	Yes	Results p10
23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No as no identifiable data was removed from the ward	See methods p6-7
Domain 3: analysis and findings				
Data analysis				
24	Number of data coders	How many data coders coded the data?	2	
25	Description of the coding tree	Did authors provide a description of the coding tree?	Thematic analysis was recorded as an excel spreadsheet not a tree	

26	Derivation of themes	Were themes identified in advance or derived from the data?	Data derived	See methods p6-7
27	Software	What software, if applicable, was used to manage the data?	Spreadsheet and word processing software	See methods p8
28	Participant checking	Did participants provide feedback on the findings?	No (see previous comments)	See methods p6
Reporting				
29	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>	Yes identified by participant number.	See methods p7
30	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes	
31	Clarity of major themes	Were major themes clearly presented in the findings?	Yes	See results p9-18
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes	See results p9-18

BMJ Open

“Just like a normal pain”- what do people with diabetes mellitus experience when having a myocardial infarction - a qualitative study recruited from UK hospitals.

Journal:	<i>BMJ Open</i>
Manuscript ID	bmjopen-2016-015736.R3
Article Type:	Research
Date Submitted by the Author:	14-Jun-2017
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Primary Subject Heading:	Cardiovascular medicine
Secondary Subject Heading:	Diabetes and endocrinology, Qualitative research, Emergency medicine, General practice / Family practice
Keywords:	Chest pain, Myocardial infarction < CARDIOLOGY, Diabetic nephropathy & vascular disease < DIABETES & ENDOCRINOLOGY

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7 “Just like a normal pain”- what do people with diabetes mellitus
8 experience when having a myocardial infarction - a qualitative study
9 recruited from UK hospitals.
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Abstract

Objective: The objective of the study was to investigate the symptoms people with diabetes experience when having a myocardial infarction (MI), their illness narrative, and how they present their symptoms to the health service.

Setting: Three London (United Kingdom) hospitals- Coronary care units (CCU) and medical wards.

Participants: Patients were recruited with diabetes mellitus (DM) (Type 1 & 2) with a clinical presentation of MI (ST elevated myocardial infarction [STEMI], non ST elevated myocardial infarction [NSTEMI], acute MI unspecified & cardiac arrest). 43 participants were recruited, 39 interviews met the study criteria and were analysed. They were predominantly male (n=30), aged 40-90 years and white British (18/39), just over a half were from other ethnic groups. The majority had type II DM (n=35); 24 had an NSTEMI, 10 had an STEMI and 5 had other cardiac events.

Definitions of selection / exclusion criteria: a diagnosis of MI, and DM, the ability to communicate enough English to complete the interview. Ward staff made a clinical judgement that the participant was post-treatment, clinically stable and well enough to participate.

Methods: A qualitative study utilising taped and transcribed interviews analysed using a thematic analysis.

Results: While most participants did experience chest pain, it was often not their most striking symptom. As their chest pain did not match their expectations of what a "heart attack" should be, participants developed narratives to explain these symptoms, including the symptoms being effects of their DM ("hypos"), side effects of medication (oral hypoglycaemics) or symptoms (such as breathlessness and indigestion) related to other comorbidities; often leading to delays in seeking care.

Conclusions:

While truly absent chest pain during MI among people with DM was rare in this study, patients' attenuated symptoms often led to delay in seeking attention, and this may result in delays in receiving treatment.

Data sharing: - No additional data available.

Article summary

Strengths and weaknesses

This is a study of people with diabetes experiencing an MI.

Strengths of the study include:

- contemporaneous patients' descriptions of their symptoms and illness narrative just after an MI,
- a model of how attenuated MI symptoms might alter help seeking behaviour,
- the participants were from a wide demographic background in terms of age, ethnicity and disease burden.

Weaknesses include:

- by recruiting patients from coronary care units we will not have captured markedly discrepant presentations,
- by recruiting on the basis of the ability to communicate in English we will have lost some cultural and linguistic nuance in symptom presentation.

Background

Diabetes Mellitus (DM) is a common health problem worldwide and affects 4-6% of the UK population.¹ Cardiovascular disease (CVD) is the major life threatening complication of DM in the UK.^{2 3 4} Myocardial infarction (MI) is the prime cause of excess mortality among those with DM, with a 3-fold increased risk of coronary heart disease (CHD) mortality,^{5 6} a 6-fold increased risk of myocardial infarction (MI)⁷ and a worse prognosis from MI compared with populations without diabetes.⁸

Possible mechanisms of this excess mortality risk include comorbidities such as hypertension, dyslipidaemia and chronic kidney disease. An important element in this observed increased mortality may be late or missed presentation by patients, and diagnosis by clinicians.^{9 10 11}

Up to a third of people who suffer an MI can have no chest pain; however people with DM make up a larger proportion of this group (32.6% vs 25.4% in one study).¹² However, when people with DM do have symptoms of an MI, their symptoms may often be atypical¹³ or unusual.¹⁴ Nevertheless, there is conflicting evidence around this issue: Funk found no statistically significant difference in CHD symptom presentation in people with and without DM, but did report non-significant increases in dyspnoea, neck and throat pain among those with DM.¹⁵ Kentsch found no differences between these groups in the frequency or severity of chest pain but also identified differences in the prevalence of dyspnoea.¹⁶ One review found conflicting results about differing MI symptoms among women with and without DM.¹⁷

There are several methodological reasons why these studies may have conflicting results: being underpowered,^{18 19} being unrepresentative of the population at risk,¹⁸ or recruited from highly selected hospital populations.²⁰ Survivor bias (i.e. living to tell the tale of your symptoms) may also be an important issue in a condition such as MI which has a high early mortality.²¹

There is a biological basis for altered perception of pain among people with diabetes in that cardiac autonomic neuropathy (CAN) is a complication of DM and leads to

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3 altered pain perception, meaning a patient might not experience pain caused by
4 myocardial ischaemia.²⁰
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7 Several qualitative studies have explored patients' symptoms during MI.^{22 23 24 25 26}

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9 ¹⁸ Within the general population experiencing MI, there are several issues identified
10 including; the considerable psychological impact of pain and specifically cardiac
11 pain,²⁷ cardiac symptoms that can be interpreted as pain, but also can trigger
12 symptoms such as anxiety (both as a trigger and barrier to action) and fear,²⁸
13 producing responses like uncertainty,²⁹ and denial.³⁰ Further factors identified
14 include patients not recognising their symptoms as MI, experiencing vague
15 symptoms,³¹ misattributing their symptoms,^{23 24} erroneous expectations of an MI,
16 ³¹ and the decisions patients make during their MI.³² Other factors include delays in
17 seeking care.^{30 11} Theoretical models of delay in seeking treatment specifically in
18 relation to MI have been summarised by Dracup.³³ Underestimating personal risk of
19 an MI,²³ and perceived lack of vulnerability to heart disease link to the concept of
20 "lay epidemiology" and of "coronary candidacy" i.e. not fitting assumptions about the
21 sort of person who gets a heart attack.³⁴
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31 There is a role of gender with MI symptoms and its interpretation; work exploring
32 women's experience of MI symptoms found that women with diabetes had more
33 atypical and painless MIs than men.³⁵ In studies of denial among men, there has
34 been exploration of the impact of their gender roles adversely effecting health
35 seeking behaviour.³⁶
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40 In studies specifically exploring the experience of patient with diabetes and MI, many
41 similar themes emerge. However Angerud finds a variability in the experience of MI
42 symptoms while exploring the patients' response to symptoms, perceived
43 susceptibility, and symptom interpretation (but found that MI symptoms were rarely
44 ascribed to DM).²⁵ Other studies in this population also identify breathlessness as a
45 presenting symptom, misinterpretation of symptoms; and their diabetes influencing
46 patients' decision making during events.³⁷
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53 Clinician factors
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3 The way clinicians ask about chest symptoms may be problematic. Clinicians ask
4 about “chest pain”, however the term “pain”,^{38 39} is often not used by patients
5 experiencing MI.
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9 In the current study, we aimed to address some of the limitations of previous
10 research by recruiting only DM patients with clear evidence of a recent MI,
11 regardless of their chest pain presentation, and use of a qualitative methodology to
12 explore how these patients describe their symptoms. Qualitative methods can help
13 overcome a narrow clinician focus and help develop a patient orientated view when
14 exploring symptoms of disease.^{37 40 23 41} The aim of the study was to investigate
15 the symptoms people with diabetes experience when having a myocardial infarction,
16 their illness narrative, and how they present their symptoms to the health service.
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Methods

This was a qualitative study where interviews were undertaken with patients with DM who have recently had a confirmed MI, recruited within coronary care units (CCU). Eligibility criteria included a confirmed diagnosis of MI (according to AHA criteria ⁴²), a clinical diagnosis of DM and the ability to communicate (understand and speak) enough English to complete the interview. Clinical staff identified participants and ensured they were post-treatment, clinically stable and well enough to participate. This subjective judgement was made by the clinical staff involved in participants' care as required by the ethics committee. Participants were approached as soon as possible after the diagnosis by a researcher (NB) so we could be sure that they had had an MI (usually a retrospective or working diagnosis) and to minimise recall bias about symptoms. Once invited, they were given a patient information sheet (PIS) about the study and 24 hours to decide whether to participate (see comments regarding ethics approval). The interviews took place in three London, UK hospitals. We aimed to recruit consecutive patients (but this proved unworkable) so this was a pragmatic sample. ⁴³

The interviews were semi-structured and iterative building from a topic guide to include a narrative of the course, range, character and severity of the symptoms the person experienced before and during their MI. We used a checklist of AMI symptoms based on Funk's acute myocardial infarction (AMI) symptom list. ¹⁵ This is distinct to Diamond and Forrester's classification of angina typicality. ⁴⁴ The checklist was worked through to ensure symptoms were absent and not just omitted. Ideas about expected symptoms of an MI, and symptom attribution were also explored as people often develop complex narratives about their illnesses. ⁴⁵ We also explored participants' thoughts about their illness, treatments they had attempted, motives and triggers for seeking help, awareness and knowledge of the symptoms of a heart attack.

Interviews were audio recorded, field notes and baseline patient information were noted. Details gathered included the type of MI (ECG changes, troponin level, clinical assessment), the patients' demographics, co-morbidities (type and duration of DM,

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3 other disease), risk factors, family history, medication use and information that might
4 impact on symptom perception, from the informant and their medical records. All
5 participants were allocated a code number to link their data together and then
6 anonymised (apart from the consent form) so that identifiable data did not leave the
7 ward setting.
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12 The audio taped interviews were transcribed verbatim and manually analysed using
13 a thematic framework approach,^{22 46} using word processing and spreadsheet
14 software. Agreement was specifically sought between reviewers about the
15 classification of symptoms as either typical or atypical as outlined by Funk.¹⁵ Two
16 independent researchers (NB, DDC) read the transcripts and analysed the data
17 using the following steps: familiarisation, identifying a thematic framework, indexing,
18 charting, mapping and interpretation. Throughout this process, transcripts were
19 repeatedly re-read to focus on specific points and ideas, to verify the presence of the
20 themes and sub-themes that are identified and ensure the context of the themes has
21 been preserved. There was then a dialogue between all the researchers which was
22 reflexive in nature linking the findings back to the study's aims. The analysis was
23 deductive or theoretical in approach in that we were looking for themes around
24 diabetes and myocardial infarction, and bounded by an expectation of probable
25 reduced or absent pain symptomatology and this shaped our topic guide and
26 approach to the data. However, the analysis was also inductive in nature, in that we
27 needed to derive themes from the data, in as much that if there were no pain
28 symptoms during the MI, we needed the participants and their narratives to tell us
29 what they did experience. The themes around reporting of symptoms is semantic
30 (or a surface meaning) in that we are largely reporting the participants' descriptions
31 of their experience. However, the explanatory models around what participants
32 thought caused their symptoms and reactions to those symptom is a much more
33 latent thematic or interpretive analysis.²² Representative quotes (with consent)
34 were used and have identifying details to link the theme to the participants'
35 characteristics.
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53 The lay term "heart attack" is used extensively in the transcripts; this can have a
54 broad popular meaning but we will assume is used by participants to suggest a
55 myocardial infarction.
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3 Ethical approval for this study and the use of quotes was obtained from the
4 Hertfordshire Research Ethics Committee. (Project no: 11/EE/0045). The committee
5 requested that we allowed a “cool off” period of 24 hours from approach to obtaining
6 consent. Data protection and local hospital trust R&D policies were followed.
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8 Consent was not originally sought to disclose the full interview transcripts.
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11 Patient involvement

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14 The original idea for this study was based on a clinical encounter in general practice.
15 A patient consulted MJ his GP, having suffered a severe MI despite having minimal
16 symptoms and subsequently developed severe heart failure. Before his death, this
17 patient agreed to support research in this area and filmed a brief video of his
18 experiences. A broader study (with same research question but a different
19 methodology) on this field was presented and supported by the North East London
20 Diabetes Research Network Lay Panel Meeting in 2011. Patients’ narratives
21 constitute the data underlying this study.
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Results

Forty three participants were recruited from the participating hospitals, however 4 interviews proved unusable due to not meeting study recruitment criteria on detailed case review and were excluded, resulting in a total of 39 participants' data available for analysis. Data on those who declined to participate was not recorded as it would have placed an additional burden on ward staff. The interviews had a mean duration of 20mins 33 sec (with a range of 5 mins 14 secs to 48mins 46 secs) and were all undertaken by one interviewer; NB. The study comprised of 30 men and 9 women; with an age range of 40-90, 35 participants had type 2 DM and 4 had type 1 DM. All participants had confirmed acute coronary syndrome; 24 had NSTEMIs, 10 had STEMIs and 5 had other MIs (acute MI-unspecified including 4 cardiac arrests). Their ethnic categories were White British (n=18), Asian/ south Asian (n=7), African or Afro-Caribbean (n=3) and others (n=5) e.g. Turkish, Maltese etc. A number (n=6) declined to state their ethnicity or instead identified their religious affiliation e.g. "Church of England", "Jewish" etc. One interview was done via an informal family translator but frequently family members would participate in the interview (in 2 interviews), clarifying the order of events or reminding the participant about elements of their illness narrative (which may have been clouded by their illness including cardiac arrest or treatment such as strong opioid analgesics). Participants were usually approached to participate the day following admission, or the Monday following a weekend admission and then interviewed usually the following day after consenting to participate as per our ethics approval. Data saturation was achieved. Each participant was given a study number between 1 to 43 and quotes are linked e.g. participant 22 (P22)

Table 1: description of participants

Participant	Age range	Type of DM	Duration of DM range (years)	Treatment of DM	Type of MI
1	70-79	2	10-19	OHG	NSTEMI
2	50-59	2	10-19	OHG/ In	NSTEMI
3	80-89	2	10-19	OHG/ In	Acute MI unspecified
4	40-49	2	0-9	OHG	NSTEMI
5	70-79	2	20-29	OHG	NSTEMI
6	50-59	2	10-19	In	NSTEMI
8	70-79	2	10-19	OHG	Acute MI unspecified
10	70-79	2	10-19	OHG/ DIET	STEMI
11	50-59	1	10-19	In	STEMI
13	60-69	2	NR	OHG/ In	NSTEMI
14	80-89	2	0-9	OHG	STEMI
15	60-69	2	0-9	OHG	STEMI
16	70-79	2	0-9	OHG	NSTEMI
17	60-69	2	>10	OHG +	NSTEMI
18	70-79	2	Nr		Acute MI unspecified
19	60-69	1	40-49	In	NSTEMI
20	80-89	2	0-9	OHG	NSTEMI
21	70-79	2	>10	OHG	Acute MI unspecified/ cardiac arrest
22	60-69	2	NR	OHG	NSTEMI
23	60-69	2	0-9	OHG	Acute MI unspecified / cardiac arrest
24	70-79	2	10-19	OHG	NSTEMI/ cardiac arrest
25	70-79	2	>25	OHG/In	STEMI
26	50-59	2	10-19	OHG/ In	STEMI
27	70-79	2	0-9	OHG	STEMI/ cardiac arrest
29	50-59	1	30-39	In	NSTEMI
30	60-69	2	10-19	OHG + / In	NSTEMI
31	40-49	2	0-9	OHG	STEMI
32	80-89	2	>20	OHG+	NSTEMI
33	60-69	2	10-19	OHG+	STEMI
34	60-69	2	10-19	OHG	STEMI
35	50-59	2	0-9	Diet	NSTEMI
36	40-49	2	20-29	OHG/ In	NSTEMI
37	60-69	2	0-9		NSTEMI
38	70-79	2	10-19	OHG	NSTEMI
39	50-59	2	10-19	OHG/ In	NSTEMI
40	40-49	1	30-39	OHG/ In	NSTEMI

41	90-99	2	30-39	In	NSTEMI
42	50-59	2	0-10	OHG	NSTEMI
43	60-69	2	10-19	OHG	NSTEMI

Cases 7, 9, 12 and 28 not included as did not meet study criteria

Key

Treatment key: OHG oral hypoglycaemics eg Metformin/ glicazide etc, In –insulins, OHG + oral hypoglycaemics + other drugs eg gliptins/ glitazones

Themes

The analysis of the data led to the identification of the following themes and sub themes.

Symptoms

- Typical vs atypical presentations
 - Atypical presentations
- Absence of pain

Attribution and consequences

- Attributing symptoms to co-morbidities
 - Ascribing symptoms to DM
 - Ascribing symptoms to hypoglycaemia
- Delay in seeking help
- Gradual onset of symptoms
 - Multiple symptoms
- Lack of awareness of MI symptoms or their increased risk of MI
 - Experience of repeat MIs
- Language of pain
- Knowing “something was wrong”

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However, these themes are not distinct. The nature of obtaining patients' narratives means that there are complex, inseparable relationships in concepts and ideas, with a continuum across themes and subthemes.

Symptoms

Participants described a wide range of symptoms, primarily around chest pain and discomfort. However, other symptoms associated with MI such as sweating and breathlessness were described, as well as a series of symptoms that are not usually associated with MI presentations. With regard to chest pain, we found a range of symptom presentations.

Typical versus atypical presentations.

Chest pain of a specific character is regarded as the classic symptom of MI and was present in most of these interviews;

"It was like your chest was being crushed." (P3)

Many of these descriptions catch this essence of a typical MI;

"Err a real dull ache and like someone is screwing up, like a tight chest just really tight, like someone is squeezing it inside....yeah like a really, really dull pain"... "it started hurting and made me feel really ill ...but then I went really pale & started sweating .. absolutely saturated.. just a really tight chest and sore like, as if there was a weight directly on top of me". (P 11)

Most of those in the study experienced some typical symptoms. However, typical symptoms with a recent chronology (necessary to suspect MI) was not always present or immediately apparent in the interviews.

Some experienced sweating; regarded as a typical MI symptom;

"My night clothes were soaking wet." (P3).

Breathlessness was also experienced either with pain or separately, which although classed as a "typical" symptom [23], is not generally recognised by clinicians to be suggestive of an MI;

1
2
3 *"I can't breathe, you couldn't breathe, my wife she phone a medic ... No you*
4 *got the pain and you can't breathe...you think you're gonna die for the lack of*
5 *breath", (P14)*
6
7

8
9 *"Like somebody's pushing me...and I'm short of breath and then it was getting*
10 *worse and it start burning". (P35)*
11

12 Atypical pain

13
14
15 Some of those in this study sometimes narrated their experience of a diffuse and
16 ambiguous set of symptoms that may not raise suspicion of MI;
17

18
19 *"It feels like something crawling up my arm... and it bites deep in there...the*
20 *only way I can describe it, it feels like someone is in there with claws and*
21 *they're tearing at your inside. Just screaming and pulling at it. Very, very*
22 *strange pain indeed", (P24)*
23
24
25

26
27 although this person later describes quite typical sounding symptoms. Others
28 described the quality of their pain;
29

30
31 *"It was just sticking pain, it was just a really pain, stay there for about 3*
32 *hours", (P30)*
33

34
35 *"Like a normal pain, it wasn't a pain, actually it was dull". (P26)*
36

37
38 These quotes raise the issue of participants' use of language which is discussed
39 later.
40

41
42 The following quote illustrates a mixture of some typical and atypical symptoms;
43

44
45 *"I can feel something happening you know, my chest, had very bad pain in my*
46 *arm, my neck and my leg, I couldn't move... Yeah sharp pain, very sharp*
47 *...Somebody was pressing my, you know, chest...My back... All the way up to*
48 *the waist...I couldn't breathe you know. I get very deep breath, I tried to do it*
49 *but it didn't go, somebody was choking me". (P5)*
50
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53
54 The inseparability of these two types of symptoms (typical/ atypical) is raised in the
55 discussion.
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3 Symptoms of weakness and tiredness were also reported around the timing of the
4 MI. One participant could not walk and said;

5
6
7 *"It's just the sheer um lethargy really, I just couldn't do anything...I wasn't*
8 *giddy and I wasn't in a lot of pain, I just couldn't sort of come to, I was, I*
9 *couldn't put one foot in front of the other. I was just so weak". (P10)*

12 13 Absence of pain

14
15 Some clearly stated they had no chest pain;

16
17
18 *"Nothing, nothing, no discomfort, no pain" (pre cardiac arrest), (P27)*

19
20 but this participant did have pain after being resuscitated. Another reported;

21
22
23 *"No pain, no sweating, nothing else" (pre cardiac arrest). (P23)*

24
25 Both of these participants experienced cardiac arrests, so some degree of event
26 amnesia cannot be excluded.

28 29 Attribution and consequences

30 31 32 Attributing symptoms to co-morbidities

33
34 The participants seemed to rationalise their symptoms and find a reason to dismiss
35 that the cause of their symptoms could be a "heart attack". Many attributed their
36 symptoms to other illness and causes. Most commonly, they attributed their
37 symptoms to indigestion leading to self-medication with antacids for this;

38
39
40
41
42 *"when you feel bloated and gassy and it's similar to that sort of pain. That's*
43 *why I mistook it for being indigestion.... I put it down to nerves or exercise*
44 *...but then in the early hours of Sunday morning I realised it couldn't have*
45 *been indigestion because it was paining me a great deal", (P31)*

46
47
48
49 *"I took, bicarb of soda, didn't work. I took um Gaviscon (antacid remedy),*
50 *didn't work. The antibiotics didn't work. That's when I knew, there was more to*
51 *this". (P3)*

52
53
54
55 but symptoms were also attributed to other causes that included asthma, muscular
56 aches, panic attacks, stress and importantly in this group, their DM;

1
2
3 *"Because of, I have other illness(es), like blood pressure, diabetes, I didn't think*
4 *(of MI), because I thought there is nothing wrong with my heart."* (P4).
5
6

7 These quotes also link to the theme of delay (both by patient and clinician in this
8 instance) which is discussed further on.
9

10 Ascribing symptoms to DM

11
12
13 Participants sometimes specifically attributed their symptoms to (lack) of control of
14 their DM, symptoms of DM or side effects of their medication;
15
16

17
18 *"I didn't realise I was having heart attack, so I was feeling rotten ...I was*
19 *hungry. Well I wasn't really hungry but I know, don't, diabetic, ...that's when*
20 *the pain come, and I went to bed and it woke me up around 2 in the morning",*
21 *(P17)*
22
23

24
25 *"Well dizzy, tired, again I'm dizzy all the time with diabetes, you get that, that's*
26 *part and parcel of being diabetic". (P17)*
27
28

29 Participant 3 also attributed her dizziness during her MI to her DM;
30

31
32 *"Not fainting, but you know dizzy turns, because I do get these dizzy turns.*
33 *You see, this is all in with the diabetes you see". (P3)*
34
35

36 Ascribing symptoms to hypoglycaemia

37
38 Patients when experiencing some symptoms, particularly sweating and feeling
39 unwell perceived themselves to be experiencing hypoglycaemia ("Hypo"), for
40 example;
41
42

43
44 *"because I am diabetic, right, um, I thought, initially I thought it was um low*
45 *blood sugar", (P2.)*
46
47

48
49 *"A little (of sweating) bit, but ...I didn't have my testing gear with me & I*
50 *thought that it might be a hypo at the time". (P11)*
51
52

53 Participant 3 perceived herself to be experiencing hypoglycaemia;
54
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1
2
3 *"That's when I knew, there was more to this (symptoms) and I had, I don't*
4 *know whether I had five hypo's in that week, but I was rolling all over the*
5 *place". (P3).*
6
7

8 Delay in seeking help

9
10
11 Delay in help seeking was a prominent feature in these narratives;

12
13
14 *"I think to be honest it (chest pain) came on suddenly but I tended to ignore it,*
15 *I've got one more screw to put in", (P21)*
16

17
18 *"I waited till my GP opened in the morning. I called him and I told him what's*
19 *wrong, they said 'just phone the ambulance' ". (P5).*
20

21
22 This delay could be ascribed to participants' failure to attribute symptoms to MI,
23 attribution to co-morbidities, lack of symptom awareness or lack of awareness of
24 increased risk of MI; but participants often realised that something more serious was
25 occurring when their symptoms did not improve;
26
27

28
29 *"But it was there too long, so I said 'could be heart attack' ". (P30)*
30

31
32 Often participants had dismissed or explained away these one off or minor
33 symptoms and did not think much of them, except with hindsight;
34

35
36 *"more during the week. Nothing sharp... it was just a niggling thing, it just*
37 *came and then it went away ... you just didn't think too much of any of these*
38 *factors in isolation; but together". (P31)*
39
40

41
42 With others, denial was behind their delay;

43
44 *"Well I thought it was a heart attack but I didn't really want to admit it at the*
45 *time. Anything other than a heart attack". (P17)*
46
47

48 49 50 Gradual onset of symptoms

51
52
53 For some participants part of this delay was the gradual rather than sudden onset of
54 symptoms;
55
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1
2
3 *"Well no ...it had happened a fortnight before"... "Sat in the chair for about*
4 *20mins and then it went so then I said to my wife, I told her 'If it happens*
5 *again I would be calling the doctor' ". (P20)*
6
7

8 9 Multiple symptoms

10
11 The respondents often had complex narratives where chest pain was a part of the
12 symptom complex they described, but their chest pain symptom may not have been
13 the most prominent, important or distressing feature; exemplified by the following
14 quote;
15
16

17
18 *"It (chest pain) did come on suddenly ...at the same time I had this very heavy*
19 *perspiration...& this very uncomfortable tummy ache...Err all three things*
20 *hitting me at once; you don't pick one out in particular ...all those three factors*
21 *the er tummy ache the excessive err sweating and the pain in the chest um I*
22 *could point to one and say look that was the main problem.. they were all a*
23 *problem at that short period of time". (P 25)*
24
25
26
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28

29 30 31 32 Lack of awareness of MI symptoms or their increased risk of MI

33
34 Many of these respondents, despite having long standing diabetes, previous cardiac
35 events or a strong family history, seemed unaware that they were at a high risk of
36 subsequent MI;
37
38

39
40 *"I thought ...how can I have a heart attack? Right. But you see, this might be*
41 *relevant as well; both my side of my family, my mother's side and my father's*
42 *side are diabetic. My father had a heart attack as well and he died from it. My*
43 *mother had a triple heart bypass. My elder brother's had an angioplasty, right,*
44 *so it does run in the family" (P2)*
45
46
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49 50 Experiences of a repeat MI

51
52 Participants who had previous MIs might be expected to have a good working
53 knowledge of these symptoms and respond accordingly if it recurred. We found
54 however that often they did not do so;
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1
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3 *"I should have guessed, right, um, it's exactly the same symptoms as when I*
4 *had my first heart attack". (P2)*
5
6

7 Language of pain

8

9
10 The expectation of severe chest pain is key to many patients' and doctors' model of
11 what an MI should be like and is apparent in some of the previous themes. However,
12 many of these respondents had symptoms that they didn't feel reached a threshold
13 of severity that they would call "pain";
14
15

16
17 *"I suppose people would call it a pain, I don't know, I wouldn't, I would still call*
18 *it severe discomfort...dull, rather than, no it wasn't sharp.... I won't put it (pain*
19 *severity score) higher, otherwise I probably would have called an ambulance*
20 *straight away", (P20)*
21
22

23
24 *"No, it was a constant. When I say pain, ache, it wasn't a pain that was*
25 *making me double up or anything". (P25)*
26
27

28 While some struggled to conceptualise their symptoms as pain, others struggled to
29 use words to describe their symptoms;
30
31

32
33 *"It's so difficult cos it was more uncomfortable than a pain that you can*
34 *describe ... I don't know how to describe it". (P20)*
35
36

37 While others clearly had very significant pain but still struggled to articulate it;

38
39 *"Indescribable to me, I couldn't, as I sit here I can't describe it... I had severe*
40 *pain and it was; I don't know how you break it down into words". (P19)*
41
42

43 Knowing "something is wrong"

44

45
46 Frequently participants had a "gut feeling" that there was something wrong or a
47 strong emotional response to their symptoms;
48
49

50 *"You know, I could sort of feel that there was something wrong", (P2).*
51

52
53 *"And I thought I can't do this, I got to get 'elp, and that's when I dialled 999...*
54 *and, you know, everything was going wrong, and I just couldn't figure out".*
55 *(P3).*
56
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3 A “sense of doom” is often associated with the presentation of MI, but in this group
4 only a few participants reported a strong sense of impending death;
5
6

7 *"I felt as if I was going to die (anxious voice)". (P6)*
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Discussion

We found that patients with DM who experienced an MI exhibited a wide range of symptoms from very classical presentations to very mild symptoms.²³ Patients often were unclear what caused their symptoms.⁴⁷ This diagnostic confusion or uncertainty appears periodically to have been mirrored by clinicians.^{9 24}

The symptoms experienced in this group ranged from those that may be expected by health care professionals, to more atypical symptoms with patients using unusual descriptive terms. The variation in experiences highlights the difficulty for both patients and healthcare providers to correctly attribute these symptoms to a cardiac event.

Patients with DM will often have other significant co-morbidities which can be attributed to their symptoms e.g. breathlessness from chronic obstructive pulmonary disease (COPD) rather than an MI. However, there seems to be an important area of confusion from symptoms related to DM and its control, that can lead to a misattribution of pain symptoms away from a new onset MI. A specific issue among this group is the impact of MI symptoms which were perceived as a side effect of medication (particularly insulin and oral hypoglycaemics). Interpreting episodes of hypoglycaemia and sudden onset MI seems to be particularly challenging with an overlap of many similar symptoms and their sudden onset.²⁵

We found participants had a lack of knowledge of MI symptoms, were falsely reassured by the lack of severe pain or did not conceptualise their milder chest discomfort as chest pain. These factors may all lead to denial or confusion and therefore delay in seeking care.³³ Delay in seeking medical attention during an MI, will have significant prognostic implications.

As the participants' symptoms did not fit with their preconceived ideas of an MI,²⁵ they ascribed it to other less serious causes, or importantly attributed their symptoms to their DM, medication side effects or "hypos"; which is a novel and important finding. The attenuated chest pain competing with other, perhaps more distressing symptoms and so being "crowded out" from the illness cognition of a possible MI, has not been previously reported.

Strengths

Within this study we have reported contemporaneous symptoms from a well described patient group, who can be characterised by their MI diagnosis. We have captured a wide range of participants with MI, by using biochemical confirmation of diagnosis wherever possible, but also by including clinical diagnoses (e.g. for cardiac arrests). Unusually for a qualitative study we have a relatively large number of participants, who were interviewed as early as possible (or allowed to) after the event to reduce recall bias.⁴⁸

Limitations

Despite recruiting participants on the basis of their MI diagnosis, but not specifically on chest pain presentations, participants are likely to have initially volunteered chest pain symptoms to get admitted to a coronary care unit. Markedly discrepant MI narratives are less likely to be represented in this study, as are silent MIs, as they are more likely to go unrecognised and present late. Survivor bias is also a distinct possibility.²¹ While a study size of 39 is good for qualitative research,⁴⁸ it is small in comparison with epidemiological studies so this methodology is therefore unlikely to pick up rarer presentations of MI.

Recruiting on the basis of being able to converse in English will exclude the linguistic nuance of other languages and cultures; important when south Asian populations among others, have a high risk of DM and coronary heart disease. However, we did successfully capture many patients who had English as second language. Additionally the UK NHS struggles to provide reliable, accessible translation; particularly in the acute and out of hours setting, so our findings may more faithfully reflect the real world setting of these decisions and presentations.

Truncating these interviews into quotes also runs the danger of falsely dichotomising symptoms into “typical” and “atypical”. When the transcripts are read in full and in context, a more rounded picture of the event develops. This nuanced view is probably a key element that helps experienced clinicians successfully identify a potential MI, in this group of patients.

How this fits into existing literature

The findings of our study link with previous work within a broad context of psychological models of illness behaviour such as health belief models.⁴⁹ We have used our findings to adapt Rosenstock and Kirsch's health belief model⁴⁹ (see figure 1) so that the impact of DM can modify the steps in the model such as reduced pain from neuropathy during an MI reducing the likelihood of action.

Diagram here (figure 1)

The language of describing pain and particularly the difficulty of describing pain recurs within our sample. Scarry describes this as the "inexpressibility of pain"⁵⁰ and this is seen with some respondents. Others use metaphor and simile to circumvent this issue, which may be helpful to the patient but means a clinician might cognitively process such symptom descriptions as "atypical" or "non cardiac", leading to misdiagnosis and delays in treatment. The term "chest pain" is also problematic³⁸; many of these participants did not conceptualise their chest symptoms as pain and so, Miller has suggested using the term "chest sensation" instead.⁵¹

Our findings have some similarities to other studies about patients' experiences of MI.^{23 24 25 26} The similarity of symptom presentation raises the possibility that these studies are just capturing the heterogeneous array of MI symptoms and this is unlinked to any underlying physiological or pathological process such as gender or DM. However, our finding of patient misattribution of MI symptoms to DM and diabetic medication, in a group at high risk of MI, does have significant clinical implications for patients and clinicians.

Implications for further research

Despite knowing that people with DM are at much higher risk of coronary events we fail to inform patients in the UK about their increased cardio-vascular risk nor identify early those who may be developing such problems. Whether screening people with diabetes for ischaemic heart disease would be beneficial remains a key question. Possibilities include trialling patient education about their CHD risk and its

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2
3 presentation in the UK Quality and Outcome (QOF) DM check or including this
4 information within DESMOND (desmond-project.org.uk)/DAFNE (www.dafne.uk.com)
5 patient education programmes, but there would be considerable difficulty in
6 designing an educational package that could reliably help patients distinguish
7 between these two aetiological possibilities of “hypo” versus MI.
8
9

10 Implications for practice

11
12 This study could contribute towards increased awareness of MI in those with DM.
13 Patients with DM should be made aware of their increased risk of cardiac events,
14 how they present and how they differ from medication side effects and “hypos”.
15 Clinicians should carefully explore patients with diabetes and their symptoms as well
16 as their interpretation of their symptoms.
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23 a. Contributorship statement

24 All 3 authors fulfil all three of the ICMJE guidelines for authorship, MJ had the
25 original study conception and design and then supervised NB during her iBSc
26 project. NB collected all the data. NB and DDC analysed the final data set. MJ
27 wrote the final manuscript with substantial intellectual input from NB and DDC.
28 All authors approved the final manuscript.
29
30
31
32

33 b. Competing interests

34 None
35

36 c. Funding

37 Royal College of General Practitioners’ Scientific foundation board (grant SFB
38 2011-25). The original project was part of the UCL iBSc in primary health care
39 and formed NB’s dissertation, supervised by MJ.
40
41
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43

44 d. Data sharing statement

45 No additional data are available as participants only consented to quotes
46 being published.
47
48

49 Figure legend

50
51 Figure 1: How diabetes (grey boxes) might affect the “Health Belief model” during
52 MI
53
54

55 With permission from Fig 1. page 115 (adapted) from Victor J. Strecher and Irwin
56 M. Rosenstock, “The health belief model”, Andrew Baum, Stanton Newman, John
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Figure 1: How diabetes (grey boxes) might affect the "Health Belief model" during MI
 With permission from Fig 1, page 115 (adapted) from Victor J. Strecher and Irwin M. Rosenstock, "The health belief model", Andrew Baum, Stanton Newman, John Weinmar, Robert West, Chris McManus (eds.), (1997), "Cambridge Handbook of Psychology, Health and Medicine, 9780521436861, Cambridge : Cambridge University

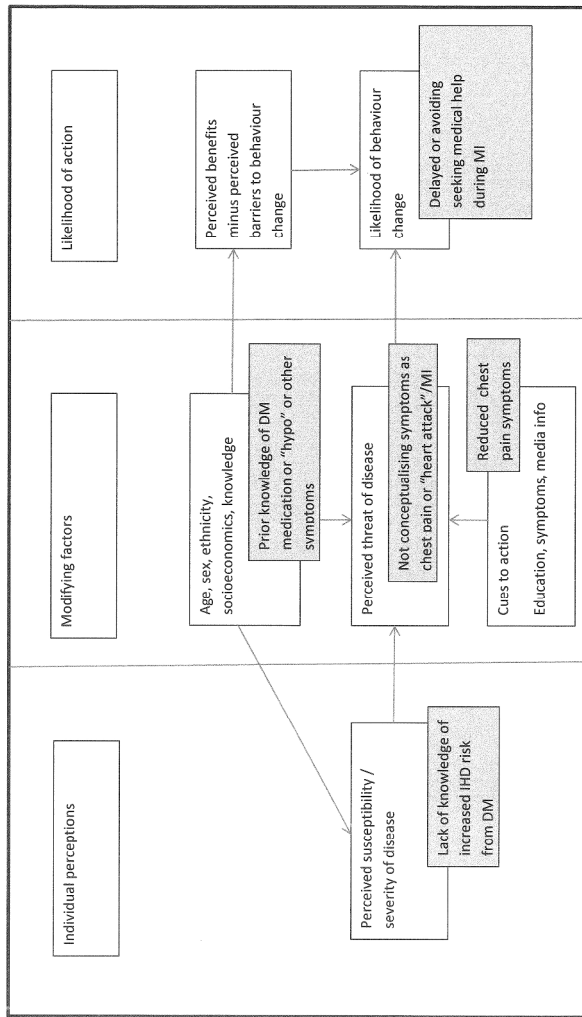


Figure 1- How diabetes (grey boxes) might effect the health belief model during MI

296x419mm (300 x 300 DPI)

	Item	Guide questions/description	Author completed	Location (using PDF pagination)
Domain 1: Research team and reflexivity				
Personal Characteristics				
1	Interviewer/ facilitator	Which author/s conducted the interview or focus group?	NB	See Methods p7
2	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	MD MSc (MJ) undergraduate (NB), BSc (DDC)	Online submission details
3	Occupation	What was their occupation at the time of the study?	Sen Lect (MJ), MB BS / iBSc student (NB), student/junior doc (DDC)	p1
4	Gender	Was the researcher male or female?	Both genders	Not documented
5	Experience and training	What experience or training did the researcher have?	MJ extensive research and research supervision, NK / DDC developed expertise during study	Not documented
Relationship with participants				
6	Relationship established	Was a relationship established prior to study commencement?	No but there was a "cool off" period between approach and consent	Methods p7
7	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	Information as set out in pt info leaflet as agreed by IRC/ ethics committee	Methods section p7
8	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	NK identified as medical student, MJ as academic and clinician	Patient information sheet (PIS) available on request

1	Domain 2: study design				
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3	Theoretical framework				
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9	9	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	Thematic analysis (Ritchie and Spencer)	Methods section p 8
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17	Participant selection				
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20	10	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>	Pragmatic sample	Methods section p 7
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28	11	Method of approach	How were participants approached? <i>e.g. face-to-face, telephone, mail, email</i>	Prior selection by clinical team (to establish well enough to participate), approach with PIS by researcher, and “cooling off” period	Methods section p 7
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35	12	Sample size	How many participants were in the study?	43 recruited, 39 analysed	Results section p10
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40	13	Non-participation	How many people refused to participate or dropped out? Reasons?	Numbers who refused to participate was not recorded. Two participants requested the interview to be terminated before completion.	Results section p10
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46	Setting				
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49	14	Setting of data collection	Where was the data collected? <i>e.g. home, clinic, workplace</i>	On hospital ward (including coronary care unit)	Methods section p7
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54	15	Presence of non-participants	Was anyone else present besides the participants and researchers?	Occasionally patients’ relatives stayed during the interview (n=2).	Results section P10
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16	Description of sample	What are the important characteristics of the sample? <i>e.g. demographic data, date</i>	Participants (n=39) were predominantly male (n=30), aged 40-90 years and white British (18/39), just over a half were from other ethnic groups. The majority had type II DM (n=35); 24 had an NSTEMI, 10 had an STEMI and 5 had other cardiac events.	Results section table 1 p11
Data collection				
17	Interview guide	Were questions, prompts, guides provided by the authors? Was it pilot tested?	Yes	Methods section p7
18	Repeat interviews	Were repeat interviews carried out? If yes, how many?	No	Methods section p7
19	Audio/visual recording	Did the research use audio or visual recording to collect the data?	Audio-recording	Methods section p7
20	Field notes	Were field notes made during and/or after the interview or focus group?	Yes	Methods section p7
21	Duration	What was the duration of the interviews or focus group?	5-48 minutes	Results section p10
22	Data saturation	Was data saturation discussed?	Yes	Results p10
23	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	No as no identifiable data was removed from the ward	See methods p7
Domain 3: analysis and findings				
Data analysis				

24	Number of data coders	How many data coders coded the data?	Two	Methods section p8
25	Description of the coding tree	Did authors provide a description of the coding tree?	Thematic analysis was recorded as an excel spreadsheet not a tree	Methods section p8
26	Derivation of themes	Were themes identified in advance or derived from the data?	Data derived	See methods p8
27	Software	What software, if applicable, was used to manage the data?	Spreadsheet and word processing software	See methods p8
28	Participant checking	Did participants provide feedback on the findings?	No (see previous comments)	Methods section P8
Reporting				
29	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>	Yes identified by participant number.	See methods p8
30	Data and findings consistent	Was there consistency between the data presented and the findings?	Yes	Results p 10-20
31	Clarity of major themes	Were major themes clearly presented in the findings?	Yes	See results p10-20
32	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	Yes	See results p10-20