

1 **TITLE PAGE**

2 Original Article

3 **Title: 'It's not an illness, it's just bad luck': The impact of**
4 **anaphylaxis on quality of life in adults**

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8 Short running title: **Quality of life of adults with anaphylaxis**

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10 **Word count:** Abstract 249 words; Manuscript 3837 words, 1 table, 2 boxes.

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35 **Statement of contribution of each author:** RK and MT Krishna designed the study protocol; MTK,
36 APH, RB and AE provided access to and helped recruit participants and collect data; SO-O, CS and
37 KN collected data; RK and CS analysed the data. RK and wrote the paper; all authors contributed to
38 editing the paper and agreed the final version.

39

40 **Funding:** Funding for the study was provided by Department of Allergy and Immunology, University
41 Hospitals Birmingham NHS Foundation Trust. They had no involvement in the study design,
42 collection, analysis and interpretation of data, writing of the report of the decision to submit for
43 publication.

44

45 **Conflicts of Interest**

46 R Knibb: Work on the project paid for by a grant from the Department of Allergy and Immunology,
47 University Hospitals Birmingham NHS Foundation Trust .

48 AP Huissoon: Speaker fees ALK Abello.

49 R Baretto: Sponsorship to attend a conference ALK Abello, Novartis. Honoraria for lectures and an
50 educational grant from Thermofisher.

51 A Ekbote: None.

52 S Onyango-Odera: None.

53 C Screti: Work on the project paid for by a grant from the Department of Allergy and Immunology,
54 University Hospitals Birmingham NHS Foundation Trust.

55 K L Newman: Work on the project paid for by a grant from the Department of Allergy and
56 Immunology, University Hospitals Birmingham NHS Foundation Trust.

57 Mamidipudi T Krishna:Sponsorship to attend a conference ALK Abello. Educational grants from
58 Thermofisher and MEDA.

59 **Abstract**

60 **Background:** An increasing number of adults are being diagnosed with anaphylaxis, but its impact on
61 health-related quality of life (HRQoL) is not known.

62

63 **Objective:** The aim of this study was to explore the impact of anaphylaxis on HRQoL of newly
64 diagnosed adults.

65

66 **Methods:** Interviews were conducted with 13 adults (aged 40-71; 5 males) with anaphylaxis (meeting
67 WAO diagnostic criteria) to drugs, food, venom or spontaneous anaphylaxis, recruited using
68 purposive sampling from allergy clinics in Birmingham, UK. Data was transcribed verbatim and
69 analysed using thematic analysis.

70

71 **Results:** Four themes were generated from the analysis: the journey from fear to frustration; the need
72 to maintain a healthy identity; control over uncertainty; and the supportive role of others. Participants
73 described their first experiences of anaphylaxis as frightening. Managing the condition was associated
74 with frustration and anxiety, in part due to uncertainty regarding when anaphylaxis might occur.
75 Participants did not consider their allergy as an illness and wanted to retain an identity as a healthy
76 person. They felt a strong need to have control over their anaphylaxis so that it did not take over their
77 lives. The support from others was extremely important, but a lack of understanding of anaphylaxis
78 sometimes hindered that support.

79

80 **Conclusions and clinical relevance:** Anaphylaxis has an adverse impact on the HRQoL of adults
81 irrespective of the cause. More information about anaphylaxis and its management from health care
82 professionals may help patients gain a sense of control over their condition and reduce the worry and
83 anxiety associated with it.

84

85 **Key words:** anaphylaxis; quality of life; adults; fear; frustration; control; social support

86

87

88

89 **Abbreviations**

90 BSACI: British Society for Allergy and Clinical Immunology

91 EAACI: European Academy of Allergy and Clinical Immunology

92 GA: General anaesthesia

93 HRQoL: Health-related quality of Life

94 NAP-6: National Audit Project-6

95 WDEIA: Wheat-dependent exercise-induced anaphylaxis

96 WAO: World Allergy Organisation

97

98 **Introduction**

99 Anaphylaxis is a potentially life-threatening systemic hypersensitivity reaction usually characterised by
100 mucocutaneous symptoms and cardio- and/or respiratory compromise requiring prompt administration
101 of injection adrenaline alongside supportive emergency management (1). Hospital admissions from
102 anaphylaxis increased by approximately 615% in the UK between 1992-2012 (2). We and others have
103 shown that food allergy is the main cause of anaphylaxis in the children, as opposed to adults, where
104 other causes including drugs, spontaneous anaphylaxis and insect stings usually account for majority
105 of cases (3-5). Whilst patients may carry the diagnosis of food allergy into adulthood, Kamdar et al (6)
106 have recently reported that at least 15% of patients with food allergy may present during adulthood.
107 Most cases of anaphylaxis occur in a community setting although another important scenario is peri-
108 operative anaphylaxis during general anaesthesia (GA), usually characterised by severe cardiovascular
109 collapse culminating into cardiopulmonary arrest (7). A recent National Audit Project-6 (NAP6) carried
110 out under the auspices of The Royal College of Anaesthetists estimated an incidence of peri-operative
111 anaphylaxis as ~1 in 10,000 anaesthetics procedures (8). Whilst peri-operative anaphylaxis is usually
112 relatively more severe than anaphylaxis occurring in a community setting, patients in the latter situation
113 have a clear recollection of the episode as opposed to the former where they were advised regarding
114 the diagnosis following recovery. This contrasting difference may potentially have an impact on the
115 way anaphylaxis might be perceived by patients in these different settings.

116
117 The risk or experience of anaphylaxis has been shown to have an impact on health-related quality of
118 life (HRQoL). QoL is described as an individuals' perception of their position in life in the context of
119 their culture and their values, in relation to their goals, expectations, standards and concerns (9). It is
120 a broad ranging concept affected in a complex way by the person's physical health, psychological state,
121 level of independence, social relationships, personal beliefs and their relationship to salient features of
122 their environment (9). HRQoL is seen as a subset of QoL, referring specifically to an individual's
123 perception of their health and is focused on physical, mental and social well-being (9). Research
124 examining severe food allergy has found that it has an impact on the HRQoL of children and adolescents
125 and their families (10) and those with a history of anaphylaxis due to food allergy have reported poorer
126 QoL and greater anxiety than those with no such history (11). Qualitative research has shown that
127 anaphylaxis in adolescents with food allergy has an impact on their social lives due to limited food

128 choice and having to carry medication. Adolescents also report a lack of knowledge and fear about
129 using an adrenaline auto-injector and low confidence in asking about ingredients in foods which can
130 hamper effective self-management (12,13). Similar findings regarding the impact on QoL have been
131 reported for those with anaphylaxis to venom (14) and to drugs (15,16).

132

133 Only one study has examined the psychological experience of anaphylaxis in adult patients. Walklet et
134 al (17) interviewed 7 adult patients with anaphylaxis to venom, drugs, food-dependent exercise-induced
135 anaphylaxis, or spontaneous anaphylaxis. Thematic analysis revealed that controllability of anaphylaxis
136 was very important. It was seen as a distressing experience and participants felt a sense of conflict
137 where they attempted to maintain an identity as a healthy person whilst acknowledging the seriousness
138 of their condition.

139

140 There are no known qualitative studies that have specifically explored the impact of anaphylaxis on the
141 HRQoL of patients who have been diagnosed with anaphylaxis as an adult. Qualitative research can
142 provide rich and detailed data from the patient's perspective and is particularly useful in under-
143 researched areas. This study aims to explore the impact that adult-onset anaphylaxis has on HRQoL
144 using semi-structured interviews.

145

146

147 **Methods**

148 ***Design***

149 This study was qualitative and utilised semi-structured interviews to elicit experiences of anaphylaxis in
150 adults and how this affected their HRQoL. The study received a favourable ethical opinion from the
151 South Central - Berkshire B Research Ethics Committee (16/SC/0238) and all participants gave written
152 informed consent.

153

154 ***Participants***

155 Thirteen patients (mean age 56.78, range 40-71 years; 5 males), diagnosed with anaphylaxis (adult
156 onset) to food (n=2), drugs (n=2), wasp venom (n=6), wheat-dependent exercise-induced anaphylaxis
157 (WDEIA) (n=1) and spontaneous anaphylaxis (n=2) were recruited from the allergy clinic in University
158 Hospitals Birmingham NHS Foundation Trust, U.K. (see Table 1). Purposive sampling was used to
159 ensure the sample included a broad range of aetiology. The diagnosis was confirmed following
160 specialist allergy evaluation and all cases met the World Allergy Organization (WAO) diagnostic
161 criteria (1, 18). A systematic clinical history was obtained in all patients followed by appropriate
162 investigations as dictated by clinical history and differential diagnoses considered. The clinic follows
163 British Society for Allergy and Clinical Immunology (BSACI) and/or European Academy of Allergy and
164 Clinical Immunology (EAACI) guidelines for diagnosis and management of common allergic
165 conditions. Patients were excluded if they were unable to give informed consent for research, or
166 unable to communicate in English.

167

168 ***Procedure***

169 Potentially suitable participants were identified from the clinic database or those attending the clinic
170 were approached. A patient information sheet was provided and those interested in taking part were
171 asked to contact the research team who then arranged a suitable date and place for an interview. A
172 written informed consent was obtained.

173

174 A semi-structured interview schedule was developed through input from experts in the field (including
175 a consultant allergist and a health psychologist), a review of relevant literature and consultation with
176 patients. This acted as a guide in the interview to ensure the aims of the study were met. It was

177 based on key areas of HRQoL with questions formulated to include physical, social, psychological
178 and environmental issues to ensure a holistic view of the impact of anaphylaxis on HRQoL was
179 elicited from participants. Example questions included 'How do you find dealing with anaphylaxis on a
180 day to day basis?' and 'What concerns you about your anaphylaxis?' The full topic guide can be
181 found in the online supplement. Interviews were conducted in person at the patient's home or at
182 Aston University (n=10), or *via* Skype (n=1) or by telephone (n=2) and lasted between 45 and 90
183 minutes.

184

185 ***Data Analysis***

186 Interviews were audio-taped, transcribed verbatim and all participants were given pseudonyms (which
187 are used in the results section). Transcription was conducted after each interview and data was
188 analysed using thematic analysis, following the steps outlined by Braun and Clarke (19), to identify both
189 common issues and differences across interviews. Transcripts were read a number of times to ensure
190 familiarisation with the data and at this stage, patterns in the data were noted. Codes were then
191 generated that were based on the meaning that emerged from the data. Codes that were similar were
192 organised together and any commonalities and differences within and across accounts were identified.
193 Initial themes were then developed from these codes. These themes were reviewed and and compared
194 against coded text passages from the interviews to check that the themes represented the content.
195 This analysis was undertaken by two authors (RK and CS) independently and results were then
196 compared and discussed. Themes did not differ in content between the two authors and a consensus
197 on the names of themes was reached after discussion and comparison of content; illustrative quotes
198 were then identified. No new themes emerged from the data after ten interviews, indicating we had
199 reached theoretical data saturation.

200

201

202

203 **Results**

204 Four themes were drawn from the data through thematic analysis: The journey from fear to frustration;
205 the need to maintain a healthy identity; control over uncertainty; the supportive role of others.

206

207 ***The journey from fear to frustration***

208 The theme of the journey from fear to frustration describes the fear felt during an anaphylactic
209 reaction and what the symptoms might mean and the ensuing frustration of trying to manage their
210 anaphylaxis. Illustrative quotes can be found in Box 1.

211

212 Anaphylaxis was described as an extremely frightening experience by participants. When
213 experiencing it for the first time, many did not know what was happening to them or why they were
214 feeling so ill. Symptoms were so distressing that one participant felt *“Is this it, am I going to die?”*
215 *(Sarah, spontaneous anaphylaxis)*. However, this fear was not always felt during the anaphylactic
216 reaction; for some it was delayed until they saw their allergy consultant and the seriousness of what
217 had happened was explained to them. Anaphylaxis was not only an emotional and frightening
218 experience for the individual but for friends and family, especially if they were with them at the time of
219 a reaction, demonstrating the burden of allergy is not only placed on the individual but also on their
220 family and friends.

221

222 After the first frightening experience, participants' fear often turned to frustration. *“I try not to get*
223 *nervous about it but that's really difficult when you can't breathe very well.....I'm more frustrated that*
224 *is has happened in the first place....like it's the why me question.” (Jane, WDEIA).*

225 Some participants felt embarrassed and annoyed with themselves that they had let this happen,
226 suggesting it was something they could have prevented. Others wondered why it had happened to
227 them at this stage of their life. This frustration was connected to different aspects of life depending on
228 the anaphylaxis trigger. Those with food allergy were annoyed that they had to avoid food they had
229 been eating all their lives. There was also frustration felt as it was more difficult to continue doing
230 activities they had previously enjoyed, such as eating out at a restaurant. Others found it difficult to
231 go on holiday or outings where there was a high risk of the presence of wasps. When looking to the

232 future some participants felt frustrated that health care professionals could not give them definitive
233 answers about issues such as if they would need to permanently carry their adrenaline auto-injector.

234

235 ***The need to maintain a healthy identity***

236 In most accounts there was a need to be seen as a healthy person, not a patient. It was important for
237 individuals to maintain a healthy identity, to not be defined by their anaphylaxis or their allergy:

238 “[anaphylaxis] doesn’t really define me” (Maureen, cardamom). Some did not see their anaphylaxis
239 as a medical condition; rather they viewed it as a ‘one-off’ event or due to bad luck: “It’s not an illness,
240 it’s just bad luck” (Jane, WDEIA). Participants described themselves as healthy people who are not
241 usually ill or need to go to the doctor or the hospital. “They wanted to take me to hospital which I was
242 a bit upset about. I said I don’t do ill.” (Sarah, spontaneous anaphylaxis)

243

244 When experiencing their first anaphylactic reaction, most participants tried to minimise what had
245 happened to them. Those who were hospitalized after their reaction reported they “didn’t feel I should
246 take up a bed” (Richard, wasp venom). Similarly, when informed they should have called an
247 ambulance whilst experiencing their anaphylaxis, some individuals could not understand why that
248 would have been necessary. This viewpoint not only demonstrates the individuals’ attempts to
249 minimise the seriousness of their anaphylaxis but may also reflect a lack of understanding about their
250 condition. When the seriousness of their condition was explained to them, individuals seemed
251 shocked by the potentially fatal consequences of anaphylaxis. Maintaining this healthy identity was
252 also identified in participants’ accounts of managing their allergy and telling others about it: “[Telling
253 others] I suffer from anaphylaxis, it all seems so desperately dramatic I wouldn’t want to make a
254 fuss” (Pamela, wasp venom). By minimising the seriousness of their anaphylaxis adults protected
255 themselves from the reality that their condition could be fatal.

256

257 ***Control over uncertainty***

258 Participants felt a strong need to have control over their anaphylaxis and this theme highlights the
259 struggle felt by adult participants to ensure anaphylaxis did not take over their lives, so that they could
260 retain a level of independence and a sense of normality.

261

262 Maintaining control was more difficult for some participants than others, depending on the length of
263 time it took for the cause of their anaphylaxis to be identified and the type of allergen they were
264 allergic to. Maintaining any control was difficult when the cause was unknown, as they did not know
265 what they needed to avoid, to stop it happening again: *“The not knowing is, it’s a vulnerability....I don’t*
266 *want to be seen as needy” (Jane, WDEIA)*. Finding out what they were allergic to came as a relief to
267 some participants: *“So finally my life had changed and it was brilliant I know what I was allergic to”*
268 *(Maureen, cardamom)*. This provided Maureen with a greater sense of control as she now knew what
269 to look out for. However, for some participants, even knowing what caused the anaphylaxis could still
270 create anxiety, as Laura describes: *“...you feel like you are playing Russian roulette every time you*
271 *go out for a meal” (Laura, lupin)*.

272

273 Some participants allergic to wasp venom or known drugs described feeling a greater sense of control
274 over their condition as these allergens were perceived to be more easily avoidable: *“With a wasp or a*
275 *bee sting I think it is fairly straight forward...I pretty much ignore it..” (Adrian, wasp venom)*. For
276 others, in order to maintain control, a variety of coping mechanisms were used to help them feel safe.
277 These included avoiding places that may have a high risk of the presence of wasps, informing others
278 and showing them how to use their adrenaline auto-injector, reading food labels or always carrying
279 rescue medication: *“even going out shopping I’ve got an Epi-pen and always when we are out one in*
280 *my bum bag and one in my rucksack” (Louise, wasp venom)*.

281

282 ***The supportive role of others***

283 The support of friends and family, work colleagues and health care professionals was discussed by all
284 participants and was seen as very important in helping them to effectively manage their anaphylaxis.
285 This theme demonstrates the importance of social relationships in promoting good HRQoL and how
286 social support can help maintain a level of independence. Illustrative quotes can be found in Box 2.

287

288 The support provided and needed was both practical and emotional. Emotional support was offered
289 by friends, family and community groups and helped participants discuss and process their feelings in
290 relation to their anaphylaxis. Practical support included help from family in avoiding the allergic
291 trigger, such as food or wasps and most participants felt it was important for their family to know how

292 to use their adrenaline auto-injector in case of an emergency. Some participants found support from
293 wider social groups such as their church or local golf club. Here the community groups were able to
294 offer practical support to help the individual avoid their allergen. *“the golf club have also put umm err*
295 *waspinators on the patio again for my benefit” (Keith wasp venom)*. Some adults enrolled the
296 practical help of others. Keith informed his neighbours of what to do if they noticed he was
297 unconscious in the garden. By doing this he felt he was prepared for a future anaphylactic reaction.
298 Maureen was also concerned she would accidentally consume her allergen when she was alone in
299 the house. In order to feel safe she messaged her friend every morning to let her know she was fine.

300

301 Despite these high levels of support Richard commented that unless you have an allergy yourself you
302 will never understand it. This insight suggests that whilst friends and family do offer support, the
303 complex nature of allergy prevents the individuals truly feeling they are being understood.

304 *“I suppose really you don’t realise what it is like have it until you have it yourself... unless you*
305 *have had ... an anaphylactic shock you can’t really get...you don’t know what it’s like do*
306 *you?” (Richard, wasp venom)*

307

308 Although friends, family and close community networks were very supportive, some participants found
309 it difficult to get support from colleagues at work and this was often due to a lack of understanding of
310 the seriousness of the condition. One participant was having immunotherapy for wasp venom
311 anaphylaxis and felt that although the process was long it was highly important to them. Their work
312 place did not understand her need to undergo immunotherapy which caused great distress and led
313 her to contemplate resignation. Half of participants had to access emergency medical care during
314 their anaphylactic episode. Although, some credit the ambulance crew for saving their life, others
315 experienced a lack of knowledge from the emergency services, resulting in feelings of greater
316 distress.

317 *“paramedics turned up and they didn’t really know what to do, they had to get their sort of,*
318 *they had to get their first aid book out, they were ringing for support and they had not, not*
319 *come across it before” (Arthur, wasp venom)*

320

321 Lack of awareness of anaphylaxis also extended to primary care, with some family physicians
322 unaware of what services were available to help those with allergy. When presenting with symptoms
323 of anaphylaxis to a pharmacist, one adult was refused the use of an Epi-pen.

324 *"I said to the pharmacist, you do realise I am having a full blow anaphylactic reaction here*
325 *don't you? But she would not give me an Epi-pen and we had to call an ambulance"* (Jane,
326 *exercise-induced*)

327

328 This theme demonstrates the importance of social support and how a lack of support can have an
329 impact on HRQoL.

330

331

332 **Discussion**

333 This study is the first to explore the impact of adult onset anaphylaxis on HRQoL. Four themes were
334 drawn from the data: the journey from fear to frustration; the need to maintain a healthy identity;
335 control over uncertainty; the supportive role of others. These themes describe the impact anaphylaxis
336 has on physical, emotional, social and environmental HRQoL in relation to their health identity, their
337 level of independence, their social relationships and their personal beliefs about their condition.
338 There were no differences across these themes in relation to gender, age or mode of interview, but
339 some differences were noted depending on the trigger for anaphylaxis.

340

341 The journey from fear to frustration illustrates the impact anaphylaxis has on the physical, emotional
342 and social HRQoL of adults and those around them and the relationship they have with their
343 environment. The fear felt during a first reaction stemmed from a lack of knowledge regarding what
344 was happening to them. The emotional impact of anaphylaxis and fear of a reaction has been
345 reported previously, particularly by adolescents with anaphylaxis to food (20) and parents of children
346 with anaphylaxis (21). Adults in the current study also expressed feelings of frustration as they had to
347 now avoid things they never had to before. This frustration has also been reported by newly-
348 diagnosed adolescents with food allergy, who seem to struggle coming to terms with the condition
349 more than those diagnosed at an early age (13,20).

350

351 The need to maintain a healthy identity demonstrates the impact of anaphylaxis on physical and
352 psychological QoL, illustrating the conflict the participants felt between having a potentially fatal
353 condition and their personal beliefs around being healthy. Maintaining a healthy identity has been
354 reported in a number of studies with children and adolescents with food allergy (22, 23) and the
355 findings from the current study also support those by Walklet et al on adults (17). It appears that the
356 need to be seen as a healthy person and not be defined by anaphylaxis is not confined to a particular
357 age, gender or allergenic trigger. It can lead to a minimisation of the seriousness of the condition or
358 indeed having a reaction, with some participants in the current study stating they did not want to
359 'make a fuss' or ring for an ambulance. Jones et al (24) reported that a strong illness identity led to
360 better self-care in adolescents with food allergy. The identity people have in relation to anaphylaxis
361 should be explored further to identify what is optimal for effective self-management.

362

363 Maintaining control of anaphylaxis was a struggle participants had in order to retain a sense of
364 independence and continue with the kind of life they led before being diagnosed with the condition.
365 Retaining control of anaphylaxis was seen to be easier by those with drug or wasp allergy as these
366 triggers were perceived to be easier to avoid. Knowing the cause of anaphylaxis was extremely
367 important for having a sense of control and for those with food or spontaneous anaphylaxis, the
368 condition was often seen as unpredictable. The support of others, both emotional and instrumental,
369 was very important in maintaining a sense of control and being able to lead a 'normal' life. However,
370 support was not always provided, and this seemed to stem from a lack of understanding of the
371 condition, particularly from primary care, pharmacists, paramedics and work colleagues. Greater
372 understanding and awareness of anaphylaxis could help support adult patients to lead a good QoL.

373

374 This study has a number of limitations to consider. It has a small number of participants which is in
375 keeping with qualitative research, however anaphylaxis to drugs and food was under-represented
376 compared to anaphylaxis to venom. This is due in part to the presentation of adult onset anaphylaxis
377 being more common for venom than other causes. More exploration of those suffering from
378 anaphylaxis to food and drugs would be beneficial. The participants were all white and other ethnic
379 backgrounds are not represented. Further research would be beneficial for other ethnic groups. The
380 participants were recruited by clinicians who were also part of the study team, although they were
381 interviewed by a research assistant who was not part of their clinical care team. Health care was not
382 a focus of the study but clearly is important in HRQoL as demonstrated by the theme social support.
383 Participants may not have felt able to fully comment on their care from the clinic and the impact this
384 might have had on their QoL.

385

386 This study is the first to investigate the impact of anaphylaxis on the HRQoL of adults and has
387 provided insights which have implications for health care practice. There is a need for healthcare
388 professionals to be aware of the lack of understanding of the condition by patients, especially of the
389 seriousness of the condition, the impact anaphylaxis has on psychological distress and the
390 importance of social support from others. Jones et al (25) has found that joining a support group
391 improved self-efficacy and confidence in allergy management in adolescents. Such support should

392 be encouraged for adults with anaphylaxis. There is also a need to improve knowledge of anaphylaxis
393 by some healthcare professionals, particularly in primary care, and knowledge of patients. Brockow
394 et al (26) found that a structured patient education programme improved knowledge of anaphylaxis
395 and emergency management in adult patients. Other interventions such as venom immunotherapy
396 have also been shown to improve HRQoL in comparison to being prescribed an adrenalin auto-
397 injector (27) and should be encouraged for such patients. Measurement of the impact of anaphylaxis
398 on QoL in adults would be also useful in order to quantify the problem on a larger sample. A QoL
399 scale has been developed by the authors and is currently undergoing reliability and validity testing.
400 This will be a useful tool for clinicians to direct health care in the future.

401

402 **Acknowledgements**

403 We would like to thank the Department of Allergy and Immunology, University Hospitals Birmingham
404 NHS Foundation Trust for funding this study.

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500 Table 1. Participant characteristics

	Participant	Gender	Age	Ethnicity	Allergy	Occupation	AAI	<u>Mode of interview</u>
1	Keith	Male	65	White British	Wasp venom	Retired	Yes	<u>In person</u>
2	Polly	Female	56	White British	Wasp venom	Receptionist	Yes	<u>In person</u>
3	Richard	Male	70	White British	Wasp venom	Retired	Yes	<u>In person</u>
4	Paul	Male	58	White British	Wasp venom	Retired	Yes	<u>Telephone</u>
5	Arthur	Male	50	White British	Wasp venom	Employed	Yes	<u>Telephone</u>
6	Louise	Female	71	White British	Wasp venom	Retired	Yes	<u>In person</u>
7	Maureen	Female	58	White British	Cardamom	Project Director	Yes	<u>Skype</u>
8	Laura	Female	51	White British	Lupin	Researcher	Yes	<u>In person</u>
9	Jane	Female	40	White British	WDEI	Employed	Yes	<u>In person</u>
10	Alan	Male	76	White British	General anaesthetic	Retired	No	<u>In person</u>
11	Emily	Female	50	White British	General anaesthetic	IT Trainer	No	<u>In person</u>
12	Rachel	Female	45	White British	Spontaneous	Employed	Yes	<u>In person</u>
13	Sarah	Female	48	White British	Spontaneous	Childcare manager	Yes	<u>In person</u>

501 WDEIA: Wheat-dependent exercise-induced anaphylaxis

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504

505 Box 1. Illustrative quotes for the theme The Journey from Fear to Frustration

506 *"I was thinking is this it am I going to die.....it's quite frightening when it happens cos you*
507 *don't know what's happeni....what's going on."* (Sarah, spontaneous anaphylaxis)

508 *"my friends that were with me when it happened thought I'd died so they were in shock"*
509 *(Keith, wasp venom)*

510 *"I wasn't aware how serious it was until I went to see [Doctor X] 7 months later umm and*
511 *that's that was the first time that I realised"* (Keith, wasp venom)

512 *"I'd say my husband and certainly my mum umm are more worried about it now than I am"*
513 *(Emily, drugs)*

514 *"it probably effects my wife more than it does me ...she gets more agitated than I do"* (Arthur,
515 *wasp venom)*

516 *"but I can't enjoy a wet curry anymore and its annoying so so I get annoyed with it you know"*
517 *(Maureen, cardamom allergy)*

518 *"[We] used to go in the summer to a few car events... we'd meet up and have a picnic but*
519 *err and I did try I did go to one but umm there seemed to be wasps the everywhere so when*
520 *we turned and came back after an hour"* (Richard, wasp venom)

521

522

523 Box 2. Illustrative quotes for the theme The Supportive Role of Others

524 *"I text my girlfriend every morning when he's [husband] away to say I'm up you know err*
525 *because I always say if you've not heard from me by nine thirty you are to come to the house*
526 *... if somehow I had had cardamom in my food and hadn't identified it in the ingredients in*
527 *the back of the thing and I didn't get round to having giving myself the epipen I could be dead*
528 *on the floor you know" (Maureen, cardamom)*

529 *"in terms of umm that network and if you like the pastoral care ... lots of very kindly caring*
530 *people who've been wonderful and that includes my parish priest who is a wonderful man and*
531 *very understanding and easy to talk to" (Emily, drugs)*

532 *"I couldn't understand how my manager could not see the long term of the whole situation*
533 *and it was my life at the end of the day that's at risk not hers, not anyone else's, it was my life*
534 *because I had been told you could die.....12 weeks to go for this injection she [manager] said,*
535 *my god cancer patients don't get that much time off" (Polly, wasp venom)*

536 *"went to the GP the following day and told him what happened and he gave me an epipen*
537 *which is a umm basically an adrena- adrenaline injection and umm I said "well what else can*
538 *we do" and he said "well what do you mean" and I said "can I you know can I get any*
539 *treatment for it, can I get" "no not that I know of" and he sent me home ... I did ask the GP if*
540 *that [allergy testing] could be done to me and he said "well I don't know anything about that"*
541 *(Richard, wasp venom)*

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