

Assistance of family carers for COPD patients using nebulisers at home: a qualitative study

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Abstract

Objective: For many patients with chronic conditions, such as COPD, the assistance of family carers with medicines is vital for optimal treatment outcomes. The aim of this study was to identify the assistance carers provide to COPD patients using nebuliser-delivered therapy at home, and the problems experienced which may impact on the safety and effectiveness of therapy and contribute to carer-burden.

Methods: A cross-sectional, qualitative descriptive study was conducted with participants recruited from primary and intermediate care. Home interviews were conducted with 14 carers who assisted a family member with COPD using a nebuliser. Qualitative procedures enabled analysis of nebuliser-related activities and problems experienced by carers.

Results: The carer sample included 10 female and 4 male carers, with a mean age of 61 years: 11 spouses and 3 daughters. They had assisted patients with use of their nebuliser and associated medications for, on average, 4.5 years. Assistance ranged from taking full responsibility for nebuliser use to providing help with particular aspects only when required. Nebuliser-related activities included assembling and setting up equipment, mixing medicines, operating the device, dismantling and cleaning equipment. Difficulties were described with all aspects of care. Carers reported concerns about medication side-effects and the lack of information provided.

Conclusion: The study revealed the vital role of carers in enabling effective therapy. The wide-ranging responsibilities assumed by carers and problems experienced relate to all aspects of COPD management with nebulisers, and have a potential impact on treatment outcomes and carer-burden. A systematic approach to addressing carers' needs and prioritising support would be anticipated to have positive consequences for patients, carers and health services.

Keywords: COPD, nebulisers, family carers, medicines optimisation, pharmaceutical care

What is known about this topic:

- Effective management of COPD for many patients in their homes depends on the correct use of their nebuliser.
- Many patients with chronic illness depend on a family carer for assistance with medicines.
- Assistance provided by family carers is often vital for successful outcomes, but can lead to significant carer-burden.

What this paper adds:

- Family carers who provide vital assistance in the home for patients with COPD depending on a nebuliser can experience problems with all aspects of its management and use.
- Responsibilities and problems experienced by carers in nebuliser-related activities will potentially impact on both treatment outcomes and carer-burden.
- A systematic approach to supporting family carers would have positive consequences for patients, carers and health services.

1 **Introduction**

2

3 Patients with COPD may be prescribed domiciliary nebuliser therapy as part of a disease
4 management plan.[1, 2] Nebulisers are used to deliver drugs with large therapeutics doses,
5 e.g. antibiotics, or for patients, such as the elderly and infirm, who have difficulties with
6 handheld inhalers, where inhaling drug from a nebuliser using normal tidal breathing is
7 advantageous. Effective use of medicines (especially inhalation therapy) is essential for
8 successful disease management of COPD patients. Exacerbations of disease and/or
9 treatment failures may result in hospitalisation and constitute a significant burden to both
10 patients and health services.

11

12 Nebulisers are complex to use, requiring assembly of equipment, dosing, frequently mixing
13 with diluents, inhalation over several minutes, then dismantling, washing, sanitising and
14 drying the equipment.[3] Patients with COPD have physical and functional limitations and
15 often depend on help from family members who provide vital care.[4-9] Reasons for reliance
16 on carers include breathlessness, co-existing disabilities, visual impairment and arthritis.[4]

17

18 Medicines-related activities are an integral part of caring, and many patients with long-term
19 illness depend on a family carer for assistance with medicines use.[10-13] Carers' roles can
20 include monitoring and maintaining medication supplies, assisting with drug administration,
21 reminding and advising on doses and frequency, monitoring and advising on side-effects,
22 and sourcing information.[11, 12] Their level of involvement ranges from assisting with a
23 small (but often significant) number of activities to taking full responsibility for all aspects of
24 medication.[12] Although a few studies have examined the impact on family carers of caring
25 for someone with COPD, these have not examined medicines-related aspects.[6, 9, 14-16].
26 However, there is some evidence from the USA that assistance from a carer may be
27 associated with improved medication adherence in COPD patients.[17] A recent review
28 highlighted the paucity of information on the needs of family carers for people with COPD.[8]

29

30 The important contribution of family carers to health care is widely accepted and support for
31 carers has been identified as a policy priority.[18-20] The Royal College of General
32 Practitioners emphasises the importance of drawing on carers' experiences in informing
33 service development.[21]

34

35 For these patients achieving optimal therapeutic outcomes to prevent hospitalisation, will
36 depend on effective nebuliser use. Currently, little is known about the assistance family
37 carers provide to COPD patients using nebuliser therapy, and the specific problems they

38 experience. The aim of this study is to identify the roles and perspectives of carers assisting
39 such patients, and to inform strategies that will enable healthcare professionals to support
40 carers in their roles, reduce carer-burden and optimise health outcomes.

41

42 **Methods**

43

44 This was a descriptive study employing qualitative methods. Data were collected in semi-
45 structured interviews in carers' homes. Participants were identified from two settings: one
46 primary care setting comprising 38 GP surgeries and one intermediate care setting
47 (healthcare and rehabilitation team located at a major acute hospital). Together, these
48 settings enabled involvement of carers of patients whose disease management may be
49 stable in the community, and carers who assisted patients recently admitted to hospital with
50 an exacerbation, possibly indicating treatment failure. All patients eligible to participate in the
51 study were identified by collaborators at the study sites. Patients with a confirmed COPD
52 diagnosis, prescribed nebulisers/Respules[®] and/or Combivent[®] (ipratropium and salbutamol)
53 for use with a nebuliser in their home were identified. Patients with mental health problems,
54 severe cognitive impairment, were unwell or had a serious illness (e.g. advanced cancer)
55 were excluded from the study. An invitation pack was forwarded to all patients who were
56 asked to identify any relative or a friend from whom they received assistance with their
57 nebuliser. This pack also included an information leaflet and reply slip for carers. Home
58 interviews were arranged with carers who returned a reply slip indicating their willingness to
59 participate. An analysis of patients' practices and experiences of nebulisers was also
60 undertaken and has been reported separately (Alhaddad B et al, 2015).

61

62 The semi-structured interview schedule comprised structured and open questions.
63 Structured questions were used to identify the range and extent of assistance provided by
64 carers with nebuliser use. Open questions enabled detailed discussion of carers'
65 experiences and difficulties regarding all aspects of their assistance and actions taken to
66 resolve problems. The interview schedule gathered details about the assistance provided
67 with respect to decisions regarding the need for therapy, setting up and operating the
68 nebuliser, cleaning, maintenance and maintaining supplies, liaison with health care providers
69 and suppliers, and information sources. The researcher was PhD student with a pharmacy
70 background and training in qualitative methods. Her expertise in therapeutic and technical
71 aspects of nebuliser use, enabled the identification and examination of all aspects from the
72 perspectives of the carers. Informed consent was obtained with the researcher prior to the
73 commencement of each interview.. All interviews were recorded and data transcribed
74 verbatim. The Framework approach was employed in the analysis.[22] This matrix-based

75 analytical method enables a systematic approach to data analysis, whilst allowing
76 application of qualitative procedures. Initial themes were guided by the domains of the
77 interview schedule to include all aspects of nebuliser use. Qualitative procedures (constant
78 comparison) were applied within this framework to ensure that findings were a true reflection
79 of carers' practices, experiences and perspectives in all domains.
80 Data analysis was facilitated by use of the FRAMEWORK software developed by NatCen
81 specifically to support the framework method. Ethics approval was obtained prior to
82 commencement of the study.

83

84 **Results**

85

86 Response rate and characteristics of the carers

87 180 patients were sent invitation packs; 83 returned the reply slip and 60 agreed to
88 participate. 15 respondents reported that they were assisted by a family carer, 14 of whom
89 agreed to take part and were interviewed. The carer sample included 10 female and 4 male
90 carers, with a mean age of 61 years (range 26–79). Eleven were spouses and 3 daughters;
91 all living with the patient. On average, the carers reported that they had assisted with
92 nebuliser therapy for about 4.5 years and spent approximately 3.5 hours per week (range 1
93 to 10.5 hours) on nebuliser-related activities. They provided assistance with a mean of 6
94 different nebuliser-related activities (range 2 to 9) and reported encountering an average of 3
95 difficulties (range 0-9) whilst providing this assistance (Table 1).

96

97

Table 1

98

99 The results are described under three main themes: assistance in decisions regarding the
100 need for therapy including advice on doses and the need for emergency help; setting up and
101 operating the nebuliser including cleaning, maintenance and obtaining supplies; and
102 obtaining information.

103

104 Assistance in decisions regarding the need for therapy Decisions regarding nebuliser
105 therapy included the need to initiate the therapy (n=6), adjusting doses (n=1), withholding a
106 dose (n=1), or giving advice on discontinuation of therapy (n=1). Advice to use therapy was
107 in response to noticing or hearing their relative experiencing breathing difficulties, or as a
108 precautionary measure prior to an anticipated increase in the patient's physical activity,
109 which might trigger breathlessness. Carers expressed concerns with regard to knowing
110 when to initiate therapy and the frequency of dosage:

111

112 We didn't want to have it (nebuliser therapy) because... he puts on a lot of weight, he
113 fills with water, but he said – don't worry, it's better to start it straight away than to
114 wait. We used to wait until he couldn't breathe at all, you see?
115 Female, 74 yrs old, assisting for 4 yrs
116

117
118 Concerns were raised by carers about safety, the patient developing tolerance and side-
119 effects of nebulised medication. Differing perspectives of carers and patients about the need
120 for medication were sometimes revealed.

121
122 Some days he looks like he's got the shakes for that is the Ventolin[®] anyway,
123 because that does make you shake because I've been on that myself in the past and
124 yeah... that wears off doesn't it after a while, but he does, I just leave him to sit quiet,
125 I watch him, he doesn't always know that I'm watching him.
126 Female, 66 yrs old, assisting for 5 yrs
127

128 Well, when she's bad she'll use it [the nebuliser] up to four times a day; when she's
129 good maybe only once or twice. So she tries not to use it, she's stubborn; she tries
130 her hardest not to use it.

131 Female, 26 yrs old, assisting for 5 yrs
132

133 Carers reported contacting a doctor or calling for an ambulance when nebulised therapy
134 failed to relieve the patient's breathlessness. However, difficulties in recognising the
135 symptoms of an exacerbation and distinguishing them from other symptoms related to age
136 or underlying conditions were experienced. Unclear information received from healthcare
137 professionals further complicated this task:

138
139 ... the receptionist said to me "do her lips go blue?" Well her lips don't always go
140 blue. At one point they ask me is her lips blue..., and I said "no" and then we got an
141 emergency doctor in; he took her oxygen levels and said "oh my god she's got to go
142 to a hospital immediately, they're so low", and I said "blue lips is not an indication
143 necessarily because she lives on low oxygen levels anyway"...

144 Female, 60 yrs old, assisting for 10 yrs
145

146 Setting up and operating the nebuliser

147 The compressor, used to generate an aerosol from fluid placed in the nebuliser chamber can
148 be noisy in operation. To overcome this, one carer described how her mother covered the
149 nebuliser with a duvet to silence it during night-time use. The weight of the compressor could
150 be problematic, e.g. necessitating the use of a trolley on excursions. Being unable to use the
151 nebuliser in the event of a power cut, as the nebuliser required mains electricity was also of
152 concern.

153 Carers described assisting with connecting tubing between the nebuliser chamber and
154 compressor, pouring drug fluid into the medication reservoir, screwing the cap back on the
155 chamber, and connecting the facemask or mouthpiece to the device before giving the
156 nebuliser to the patient to start inhaling the nebulised dose:

157

158 He can't put the solutions in when things are bad. He doesn't understand which ones
159 to put in. He couldn't tell the difference between the two; the antibiotic and the other
160 one. So he does need somebody to make sure he is doing it properly.

161 Female, 64 yrs old, assisting for 3 yrs

162

163 Some carers reported technical difficulties; especially related to over-stretched tubing, but
164 also to the lengthy process of setting up and operating nebulisers when medication was
165 needed immediately and uncertainty regarding dilution of the medication (usually with
166 physiological saline):

167

168 Sometimes this [tubing] does come off. It sort of blows off you know and we have to
169 keep pushing it back on and that doesn't stay in there too well.

170 Female, 67 yrs old, assisting for 4 yrs

171

172 ...that's the bit that we're not sure about because sometimes he uses distilled water,
173 sometimes he doesn't put any water in and I don't know if that's right.

174 Female, 29 yrs old, assisting for 10 yrs

175

176 During nebulisation, carers may assist in fitting the mask to the patient's face and advising
177 on their breathing pattern, sometimes being concerned whether full effectiveness was
178 achieved:

179 I have to say I don't think he does enough deep breathing....I say come on breathe in
180 and breathe out.

181 Female, 75 yrs old, assisting for 0.5 yrs

182

183 *Dismantling and cleaning*

184 Dismantling the nebuliser system after use and subsequent cleaning is essential. Carers
185 described washing nebuliser parts with warm soapy water, wiping the compressor and
186 disinfecting parts with commercial detergent. Some reported that these tasks may not be
187 undertaken when they were unavailable. Difficulties in dismantling the device were reported,
188 resulting from poor manual dexterity due to arthritis, poor maintenance or understanding of
189 the nebuliser parts. In two cases, carers described incidents where the tubing was stuck and
190 could not be detached from the nebuliser. Two others expressed concerns over blocked
191 tubing which could not be cleaned properly.

192

193 *Maintenance, servicing and obtaining parts*

194 Carers invariably took responsibility for purchasing or obtaining disposable components
195 (nebuliser, facemask, mouthpiece, tubing); booking, and taking the nebuliser for servicing or
196 repair. They reported difficulties in accessing disposable parts through the hospital or local
197 surgery, and revealed health professionals were uncertain about whether (or under what
198 circumstances) different items could be provided. Other concerns included: non-availability
199 of nebuliser services, lengthy procedures for obtaining a nebuliser, lack of information on
200 maintenance and fears of being without a nebuliser if equipment failed. When relying on
201 private suppliers, the costs, practicalities of trips to manufacturers and their agents, and
202 problems obtaining required items and quantities were raised:

203

204 We bought packages from the company and you get loads of stuff you don't need.
205 You know you couldn't buy the tubes without [the nebuliser], you know on their own,
206 and that kind of thing; you're like paying £20 for a package with loads of stuff you
207 don't use.

208

Female, 60 yrs old, assisting for 10 yrs

209

210 Carers were commonly responsible for ordering and collecting supplies of nebuliser
211 medication from doctors' surgeries and pharmacies.

212

213 Obtaining information

214 Carers drew on a variety of information sources: GPs, manufacturers' instruction manuals,
215 medication leaflets and family members with medical backgrounds. A range of information
216 needs were outlined: frequency of dosage, required volume of nebuliser fluid, adverse
217 effects, nebuliser cleaning and maintenance, and actions to be taken in case of treatment
218 failure or equipment breakdown. The use of several inhaler devices (nebuliser users
219 frequently also use handheld inhalers) was a source of confusion for some carers.
220 Inconsistent information and lack of understanding of changes to prescriptions or regimens
221 also caused problems:

222 My husband is on three different inhalers, so we weren't entirely sure how they really
223 work... He was told to take them, but we weren't really sure what we were supposed
224 to be doing.

225

Female, 67 yrs old, assisting for 4 yrs

226

227 The responsibility for managing medication, with limited knowledge and understanding could
228 be stressful:

229

230 I'm not a doctor and I'm not a nurse and they mustn't view me as that... they can do
231 this, but at the end of the day [...] if something bad happened to her, I would say "is
232 that me?' 'Did I do that?"

233 Female, 60 yrs old, assisting for 10 yrs

234

235

236 Discussion

237

-Figure 1-

238

239 Figure 1 illustrates the study findings, indicating the potential impact on patients' medicines-
240 related outcomes and carer-burden.

241

242 The responsibilities assumed by carers and the problems and concerns experienced varied
243 hugely, and apply to all aspects of nebuliser use.

244

245 Previous research has acknowledged that older people with COPD depend on a carer for
246 assistance, potentially resulting in considerable carer-burden.[8, 9, 14-16, 23, 24] However,
247 in these studies there has been little focus on assistance with medicines, which is vital for
248 treatment outcomes, yet contributes to carer-burden.[25] One such study did identify, from
249 patients' and carers' perspectives, that nebulisers conferred benefits that outweighed their
250 disadvantages especially when compared to other inhalation devices, but did not discuss
251 nebuliser-related support and problems.[26] The present study details the extent of support
252 and range of activities with nebulisers for which carers assumed responsibility. This included
253 practical assistance specific to nebuliser use and maintenance, organizational and
254 therapeutic roles, such as obtaining and administering medication, making clinical judgments
255 on the need for medication and in response to side-effects, and seeking information from a
256 range of sources.

257

258 Respondents indicated several concerns which should be addressed to permit them to
259 ensure optimal nebuliser use. Currently, whilst nebuliser medication is prescribable in the UK
260 on the NHS, equipment, including compressors, nebulisers, facemasks, mouthpieces and
261 connecting tubing are not. Hence, the sources and use of equipment are not standardised,
262 with patients receiving equipment from GP surgeries, local hospitals, charities or purchasing
263 it themselves. This presents problems for patients and their carers who are themselves
264 frequently elderly. The carers commented on difficulties with obtaining equipment, the
265 associated costs, problems of getting equipment (constantly used) serviced, and the cost of
266 "disposable" items which came packaged with unneeded sundries.

267

268 Some concern was expressed regarding poor portability of nebuliser equipment and the
269 constant need for a power supply. Portable nebulisers with rechargeable battery packs are
270 commercially available. Such devices should be made available, where appropriate, to this
271 patient group.

272

273 Nebuliser equipment including the nebuliser chamber, tubing and mouthpiece requires
274 regular washing and disinfection, according to manufacturers' recommendations. Even in
275 this small sample problems associated with cleaning were evident, either due to the
276 practicalities of dismantling and cleaning the equipment or, as this activity was frequently
277 undertaken by carers, it was not done in their absence. Nebuliser medications are
278 unpreserved and inadequate cleaning and decontamination may lead to microbial
279 colonisation of equipment, posing an infection risk to the patient,[27, 28] potentially leading
280 to hospitalisation.

281

282 In addition to nebuliser-specific activities and problems, the carers expressed concerns
283 about overdosing, difficulties in determining the correct dose, care-recipient's reluctance to
284 use medication, perceived need for more information from healthcare professionals, worries
285 about disruption in medication supply, the complexities of obtaining disposable parts and
286 nebuliser maintenance, and the level of vigilance required to monitor the care-recipient's
287 condition. All have potential implications for optimal medicines use, adherence to dosing
288 regimens and therapeutic outcomes. These concerns also contribute to carer-burden.[25]

289

290 Strengths and limitations of this study

291 Carers were recruited through primary and intermediate care, permitting involvement of
292 carers of a diverse patient group. Interviews were conducted in the patient's homes,
293 enabling a detailed examination and discussion of nebuliser-related activities. There are
294 several limitations: the sample was confined to 15 people who identified themselves as
295 carers. It is possible others, who perceive they provide only limited assistance (which could
296 be vital to patient care) did not consider themselves eligible, and were therefore excluded.
297 Carers from residential homes or other community day care services who have responsibility
298 for patients, and who may face different challenges were not included. It is also possible that
299 carers experiencing the highest levels of burden were not well represented in this study,
300 being reluctant to participate due to time constraints.

301

302 Implications for policy, practice and future research

303 The UK Government recognises the important role of family carers and their contribution to
304 health care, potentially enabling older people to remain in their own homes for longer,[18] a

305 desire shared by patients and important to carers. Support for family carers has been
306 identified by the UK Department of Health, as a policy priority.[18-20] A system of support
307 that specifically includes carers and addresses their needs and difficulties should be a
308 priority for health professionals. The Royal College of General Practitioners acknowledges
309 the importance of service developments for carers being informed by their views and
310 experiences.[21] This paper provides detail on needs and problems from the perspective of
311 carers to inform future proposals. Sub-optimal domiciliary use of nebulisers by patients with
312 COPD is a potential source of treatment failure leading to hospitalisation. Thus, health
313 professionals need to identify patients who rely on carers regarding the use of their
314 nebulisers. They should ensure that interventions and consultations are arranged to enable
315 the involvement of carers, so that their roles and needs can be addressed. Future research
316 should focus on interventions to improve support for carers (especially when treatment
317 commences and regimens are changed). Potential interventions should be evaluated firstly,
318 in terms of their feasibility and acceptability to patients, carers and health professionals and
319 secondly, in terms of their impact in reducing carer-burden and optimising disease
320 management in the community.

321

322 Conclusion

323 Although the sample was small, the study demonstrated that the optimal use of nebulisers
324 by patients with COPD is inextricably linked to the roles and responsibilities of family carers.
325 A systematic approach to addressing the needs of carers is anticipated to have an impact on
326 patients' outcomes, health services and carer-burden.

327

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334

335 **Competing interests**

336 The authors declare there are no competing interests involved in this research or the writing
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338

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342 **Body giving ethical approval and reference number**

343 This study was granted ethical approval from Harrow Research Ethics Committee, REC
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347

**Table 1. The number of family carers assisting, and reporting difficulty,
with each activity (n=14)**

Activity	No. of carers performing activity	No. of carers reporting difficulty
Making decisions on the need to use the nebuliser	8	4
Supervising the nebulisation process	9	4
Setting up and operating the nebuliser	12	8
Assisting with inhaling the nebulised medication	3	1
Dismantling and cleaning the nebuliser	10	7
Maintaining supplies of disposables (e.g. tubing) and condition of the nebuliser	9	6
Maintaining supply of nebulised medication	11	4
Making decisions to seek help in an emergency	8	3
Monitoring side effects of nebulised medication	11	3
Gathering information on the use or safety of nebuliser	8	2

Figure1: Family carers who assist COPD patients with nebulisers: potential impact on treatment outcomes and carer-burden

