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Invisibility of breathlessness in clinical consultations: a cross-sectional, national online survey

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Abstract:	

Authors' response to Editor's and Reviewers' comments
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Dear Editor

Thank you for the opportunity to respond to the Editor's helpful and constructive comment. The Conclusion, and paper overall, have been considerably strengthened by addressing the issue raised.

Attached is a clean copy of the manuscript and a version with tracked changes that specifies the changes made in response to the Editor's comment.

Editor's Comments		Authors' response
1	Thank you for answering the comments of the reviewers with care. The one point that remains pertains to the strength of the conclusion. Your response to comment 4 from reviewer 1 is not exactly spot on, and I would insist on mentioning the "human rights" aspects in you final statement, wit reference to Basoglu's paper (16 references instead of 15 should be acceptable from an editorial point of view).	We greatly appreciate the opportunity to revisit comment 4 from Reviewer 1: The "punchline" should be more potent than it is. These authors have advocated that dyspnea care is a human right (Currow et al., Thorax), a concept that has been further developed in this same journal (Basoglu, 2017). What this study shows is a breach of human rights at a societal level. A sentence to that effect could conclude the research letter (quoting Basoglu). As suggested by the Editor and Reviewer, we have now incorporated the issue of "human rights" in the context of breathlessness in the Conclusion, which strengthens it considerably, and the paper overall. We have also added both references mentioned by Reviewer 1 in support of the "human rights" aspect of breathlessness and its care. We hope this would be acceptable from an editorial point of view. Please see page 5 and text below [in bold]. <u>Page 5</u> Clinicians must actively explore long-term breathlessness because one in two patients with this do not talk about it during routine clinical encounters. **Addressing long-term breathlessness proactively, systematically and empathically is a human right that patients should expect to be addressed by competent, caring clinicians [16, 17].** As clinicians rarely initiate breathlessness conversations unless prompted by patients, clinical history taking should be refined with a more effective symptom screening question designed specifically to identify the presence, severity and impact of breathlessness.

Thank you once again for the opportunity to address these comments. If there are any issues that I can clarify, please do not hesitate to contact me.

Yours sincerely,

Dr Slavica Kochovska
On behalf of the Authors

Invisibility of breathlessness in clinical consultations: a cross-sectional, national online survey

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Take home message:
Breathlessness is invisible in patient-clinician consultations. Improving clinical history taking is critical to help identify more consistently the presence and impact of breathlessness, especially for people living long-term with this disabling symptom.

To the Editor

Breathlessness diminishes the physical, mental and social wellbeing of people living long-term with this disabling symptom [1]. Identifying its impacts on patients and their families helps to inform appropriate non-pharmacological and pharmacological management [2, 3]. A randomised controlled trial suggests that clinicians are less likely to identify or manage chronic breathlessness than chronic pain [4]. Previous population studies estimate 9.5% of adults experience breathlessness [5], with 1 in 100 individuals being seriously impacted daily [6]. We conducted a population study aimed at identifying the proportion of people with breathlessness who report this symptom in clinical consultations. If discussed, we explored whether patients or clinicians (physicians; nurses) initiated the conversation and, if not discussed, whether patients would welcome such discussions.

An Australian cross-sectional, online survey using the Qualtrics platform (Qualtrics, Utah, USA) was undertaken (12 July-2 August, 2021) to recruit adults (≥18 years) representative of the Australian 2016 census population by age, sex, state/territory of residence and rurality [7]. Participants were invited by Qualtrics through its database of >800,000 registered panel members. Recruitment quotas were set for combinations of all four demographic parameters.

The survey was piloted with members of the Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT) Consumer Advisory Group (University of Technology Sydney) and 110 Qualtrics' panellists before general recruitment. Panel members provided initial informed consent when joining Qualtrics' panel. A Participant Information Sheet was provided before obtaining additional informed consent for this survey. Approval was obtained from the Human Research Ethics Committee (University of Technology Sydney; UTS HREC ETH20-5114).

Participants' self-reported data included: age, sex, state/territory of residence, postcode (to code rurality using the Australian Statistical Geography Standards [8]), height/weight (to estimate body mass index (BMI)), and smoking status. The presence and severity of breathlessness was assessed using the modified Medical Research Council (mMRC)

breathlessness scale (0-4) [9]. Higher scores indicate decreasing physical exertion before breathlessness supervenes. Analyses compared mMRC 2 with mMRC 3-4. The duration (years/months) and perceived primary cause (multiple-choice from a range of health conditions) of breathlessness were sought. Respondents with breathlessness were asked whether this had ever been discussed in clinical consultations; if so, who initiated the discussion (patient or clinician); and if not, whether they would welcome such a discussion. (Figure 1)

Demographics were described. Differences between those who did and did not initiate conversations (for both patients and clinicians), including preferences, were assessed using chi-square tests, t-tests or Mann Whitney tests as appropriate. Binary and multinominal logistic regression assessed the predictors for preferences regarding breathlessness discussions. No data were imputed. Analyses used Excel (Microsoft Office 16) and Statistical Package for the Social Sciences (SPSS) software, V28.0 (IBM Corporation, Armonk, NY; 2016). A p-value of <0.05 was considered statistically significant.

Of 10,033 survey respondents, 1,106 (11.0%) reported mMRC ≥2 for whom: mean age was 43.4 years; 53.4% (n=588) were female; most lived in metropolitan areas (74.7%; n=825); 60.7% (n=671) had a history of smoking; and 49.0% (n=423) attributed their breathlessness to a lung condition. Median breathlessness duration was 3.5 years. BMI was available for 80% of respondents, of whom 60.2% (n=492) reported being overweight/obese/very obese.

Of those with breathlessness, 69.1% (764/1,106) indicated that they initiated discussions about their breathlessness. (Figure 1) For 85.1% (291/342) of those who did *not* raise the issue themselves, clinicians did not raise the topic of breathlessness either (hereon '*invisible breathlessness*'). Of those with *invisible breathlessness*, 53.6% (156/291) indicated they would have welcomed a conversation about it. Breathlessness remained completely unexplored for 24% (72/300) of people with severe breathlessness (mMRC 3-4), of whom 45.8% (33/72) would have welcomed such discussions.

There was no significant association between breathlessness intensity and initiating conversations about breathlessness nor preferences for having such discussions. (Figure 1)

Older males were more likely to initiate a conversation, yet less likely to be asked about their breathlessness by clinicians. Breathlessness duration and a history of smoking were predictors for patient- but not clinician-initiated conversations. Clinicians were less likely to discuss breathlessness with patients who are overweight, yet those patients were more likely to welcome such a discussion. In bivariate analyses, age was the only factor in driving preferences for having discussions, and remained as such in multivariate regression when sex, smoking and level of breathlessness were included.

The survey found that 26.3% of people with mMRC ≥2 lived with unreported breathlessness, which is similar to a UK population online survey where 29% of people with mMRC ≥2 had not sought medical advice for their breathlessness [10].

The key findings are three-fold. Firstly, this study found that breathlessness is often invisible in routine clinical consultations because many patients and clinicians fail to raise the topic, at any time in the past. Specifically, 1 in 2 people with breathlessness and 1 in 4 people with severe breathlessness (i.e. housebound or unable to self-care due to breathlessness) live with the symptom and its associated impact undetected, generating unmet needs.

Secondly, clinicians rarely initiated conversations about breathlessness unless prompted by patients. Although empowering patients to raise the topic with their treating clinician and advocate for their needs is important, identifying breathlessness is a skill in clinicians' history taking and should be implemented routinely. Providing clinicians with a more optimal screening question to identify the presence, severity and impact of breathlessness may be *the* critical first step in initiating a conversation about patients' unmet needs. Such systematic inquiry would facilitate better symptom management, aligned with people's priorities.

Thirdly, breathlessness intensity did not drive these conversations. As people progressively reduce or cease their everyday activities to self-manage their worsening breathlessness, there is a risk that this modified lifestyle becomes their "new normal", whilst affecting the very basic aspects of their personhood. As effects can be experienced for years with

progressive deconditioning, clinicians must actively elicit the impact of breathlessness across the symptom's trajectory to help prevent this vicious cycle.

This study shows that breathlessness remains surprisingly invisible within the health system because patients and clinicians alike are reluctant to raise the topic during clinical encounters. Patients may have normalised their breathlessness as expected [11], adjusted their lives to minimise/avoid it [12] or feel stigmatised [13]. Clinicians may underestimate its impact [14] or feel constrained in how to constructively address it [15]. Future research should explore the barriers to communication to better understand the reasons that drive hesitancy and avoidance in discussing this debilitating symptom in routine practice. Incorporating effective symptom screening, together with education and resources for implementing evidence-based therapies, would enable better long-term symptom management.

This study included a large, nationally representative community sample (standardised to the national census), with reported rates of breathlessness similar to other general adult population prevalence estimates [6]. Although the online delivery may have limited the survey's uptake to those with internet capabilities or digital literacy, it may have positively influenced participation of people with severely limited physical function. It also facilitated recruitment independently of health service contact thus potentially capturing people who are otherwise invisible to it.

Clinicians must actively explore long-term breathlessness because one in two patients with this do not talk about it during routine clinical encounters. Addressing long-term breathlessness proactively, systematically and empathically is a human right that patients should expect to be addressed by competent, caring clinicians [16, 17]. As clinicians rarely initiate breathlessness conversations unless prompted by patients, clinical history taking should be refined with a more effective symptom screening question designed specifically to identify the presence, severity and impact of breathlessness.

Acknowledgements

The authors thank the participants who gave their time to respond to the survey. We thank Qualtrics for facilitating this project especially Daniel Chong, Sujit Singh, Rebecca Toll, Andy Rohner and Matt Lee. We are grateful to Ms. Debbie Marriott for her untiring support in preparing the manuscript for publication and facilitating team meetings for the duration of the project.

Data availability

The questionnaire used in this study is in the public domain and can be accessed at https://osf.io/fhxkc

Support statement

This study was supported by a University of Technology Sydney Faculty of Health Early Career Researcher Seed Grant (S. Kochovska) and discretionary funds held by the academic teams involved in the collection and analyses of these data.

Conflict of interest

DCC is an unpaid member of an advisory board for Helsinn Pharmaceuticals and Specialist Therapeutics, and has consulted to, and received intellectual property payments from Mayne Pharma. The other authors declare no completing interests.

Author contributions

Conception and design: SK, DCC; data collection: SK, DCC; data analyses: SK, SC, DCC; drafting the article: SK; revision for important intellectual content and final approval of the version to be published: all authors.

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Invisibility of ~~persistent~~ breathlessness in clinical consultations: a cross-sectional, national online survey

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Take home message:
~~Persistent (chronic) b~~Breathlessness is invisible in patient-clinician consultations. ~~Future work is needed to develop~~Improving ~~improved~~ clinical history taking is critical to help identify more consistently the presence and impact of ~~persistent~~ breathlessness, especially for people living long-term with this disabling symptom.

To the Editor

~~Persistent (chronic) b~~Breathlessness diminishes the physical, mental and social wellbeing of people living long-term with this disabling symptom [1]. Identifying its impacts on patients and their families helps to inform appropriate non-pharmacological and pharmacological management [2, 3]. A randomised controlled trial suggests that clinicians are less likely to identify or manage ~~persistent~~ chronic breathlessness than chronic pain [4]. Previous population studies estimate 9.5% of adults experience ~~persistent~~ breathlessness [5], with 1 in 100 individuals being seriously impacted daily [6]. We conducted a population study aimed at identifying the proportion of people with ~~persistent~~ breathlessness who report this symptom in clinical consultations. If discussed, we explored whether patients or clinicians (physicians~~, or~~ nurses) initiated the conversation and, if not discussed, whether patients would welcome such discussions.

An Australian cross-sectional, online survey using the Qualtrics platform (Qualtrics, Utah, USA) was undertaken (12 July-2 August, 2021) to recruit adults (≥18 years) representative of the Australian 2016 census population by age, sex, state/territory of residence and rurality [7]. Participants were invited by Qualtrics through its database of ≥~~more than~~ 800,000 registered panel members. Recruitment quotas were set for combinations of all four demographic parameters.

The survey was piloted with members of the Improving Palliative, Aged and Chronic Care through Clinical Research and Translation (IMPACCT) Consumer Advisory Group (University of Technology Sydney) and 110 Qualtrics' panellists before general recruitment. Panel members provided initial informed consent when joining Qualtrics' panel. A Participant Information Sheet was provided before obtaining additional informed consent for this survey. Approval was obtained from the Human Research Ethics Committee (University of Technology Sydney; UTS HREC ETH20-5114).

Participants' self-reported data included: age, sex, state/territory of residence, postcode (to code rurality using the Australian Statistical Geography Standards [8]), height/weight (to estimate body mass index (BMI)), and smoking status. The presence and severity of

breathlessness was assessed using the modified Medical Research Council (mMRC) breathlessness scale (0-4) [9]. Higher scores indicate decreasing physical exertion before breathlessness supervenes. Analyses compared mMRC 2 with mMRC 3-4. The duration (years/months) and perceived primary cause (multiple-choice from a range of health conditions) of breathlessness were sought.

Respondents with breathlessness were asked whether this had ever been discussed in clinical consultations; if so, who initiated the discussion (patient or clinician); and if not, whether they would welcome such a discussion. (Figure 1)

Demographics were described. Differences between those who did and did not initiate conversations (for both patients and clinicians), including preferences, were assessed using chi-square tests, t-tests or Mann Whitney tests as appropriate. Binary and multinominal logistic regression assessed the predictors for preferences regarding breathlessness discussions. No data were imputed. Analyses used Excel (Microsoft Office 16) and Statistical Package for the Social Sciences (SPSS) software, V28.0 (IBM Corporation, Armonk, NY; 2016). A p-value of <0.05 was considered statistically significant.

Of 10,033 survey respondents, 1,106 (11.0%) reported mMRC ≥2 for whom: mean age was 43.4 years; 53.4% (n=588) were female; most lived in metropolitan areas (74.7%; n=825); 60.7% (n=671) had a history of smoking; and 49.0% (n=423) attributed their breathlessness to a lung condition. Median breathlessness duration was 3.5 years. BMI was available for 80% of respondents, of whom 60.2% (n=492) reported being overweight/obese/very obese.

Of those with ~~persistent~~ breathlessness, 69.1% (764/1,106) indicated that they initiated discussions about their breathlessness. (Figure 1) For 85.1% (291/342) of those who did *not* raise the issue themselves, clinicians did not raise the topic of breathlessness either (hereon '*invisible breathlessness*'). Of those with *invisible breathlessness*, 53.6% (156/291) indicated they would have welcomed a conversation about it.

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There was no ~~correlation~~ significant association between breathlessness intensity and initiating conversations about breathlessness nor preferences for having such discussions. (Figure 1) Older males were more likely to initiate a conversation, yet less likely to be asked about their breathlessness by clinicians. Breathlessness duration and a history of smoking were predictors for patient- ~~initiated~~ but not clinician-initiated conversations. Clinicians were less likely to discuss breathlessness with patients who are overweight, yet those patients were more likely to welcome such a discussion. In bivariate analyses, age was the only factor in driving preferences for having discussions, and remained as such in multivariate regression when sex, smoking and level of breathlessness were included.

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The key findings are three-fold. Firstly, t~~T~~his study found that ~~persistent~~ breathlessness is often invisible in ~~many~~ routine clinical consultations because many patients and clinicians fail to raise the~~ei~~s topic, at any time in the past. Specifically, 1 in 2 people with ~~persistent~~ breathlessness and 1 in 4 people with severe breathlessness (i.e. housebound or unable to self-care due to breathlessness) live with the symptom and its associated impact undetected, generating unmet needs.

Secondly, c~~C~~linicians rarely initiated conversations about ~~persistent~~ breathlessness unless prompted by patients. Although empowering patients to raise the topic with their treating clinician and advocate for their needs is important, identifying ~~persistent~~ breathlessness is a skill in clinicians' history taking and should be implemented routinely. Providing clinicians with a more optimal screening question to identify the presence, severity and impact of

breathlessness may be *the* critical first step in initiating a conversation about patients' unmet needs. Such systematic inquiry would facilitate better symptom management, aligned with people's priorities.

Thirdly, b~~B~~reathlessness intensity did not drive these conversations. As people progressively reduce or cease their everyday activities to self-manage their worsening breathlessness, there is a risk that this modified lifestyle becomes their "new normal", whilst affecting the very basic aspects of their personhood. As effects can be experienced for years with progressive deconditioning, clinicians must actively elicit the impact of breathlessness across the symptom's trajectory to help prevent this vicious cycle.

This study shows that ~~persistent~~ breathlessness remains surprisingly invisible within the health system because patients and clinicians alike are reluctant to raise the topic during clinical encounters. Patients may have normalised their breathlessness as expected [11], adjusted their lives to minimise/avoid it [12] or feel stigmatised [13]. Clinicians may underestimate its impact [14] or feel constrained in how to constructively address it [15]. Future research should explore the barriers to communication to better understand the reasons that drive hesitancy and avoidance in discussing this debilitating symptom in routine practice. Incorporating effective symptom screening, together with education and resources for implementing evidence-based therapies, would enable better long-term symptom management.

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Clinicians must actively explore long-term breathlessness because one in two patients with this do not talk about it during routine clinical encounters. Addressing long-term

breathlessness proactively, systematically and empathically is a human right that patients should expect to be addressed by competent, caring clinicians [16, 17]. ~~Given that~~As clinicians rarely initiate breathlessness conversations ~~about it~~ unless prompted by patients, clinical history taking should be refined ~~augmented~~ with a more effective symptom screening question designed specifically to identify ~~the~~ the presence, severity and impact of breathlessness ~~of breathlessness on patients' lives and wellbeing.~~.

Acknowledgements

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Data availability

The questionnaire used in this study is in the public domain and can be accessed at https://osf.io/fhxkc

Support statement

This study was supported by a University of Technology Sydney Faculty of Health Early Career Researcher Seed Grant (S. Kochovska) and discretionary funds held by the academic teams involved in the collection and analyses of these data.

Conflict of interest

DCC is an unpaid member of an advisory board for Helsinn Pharmaceuticals and Specialist Therapeutics, and has consulted to, and received intellectual property payments from Mayne Pharma. The other authors declare no completing interests.

Author contributions

Conception and design: SK, DCC; data collection: SK, DCC; data analyses: SK, SC, DCC; drafting the article: SK; revision for important intellectual content and final approval of the version to be published: all authors.

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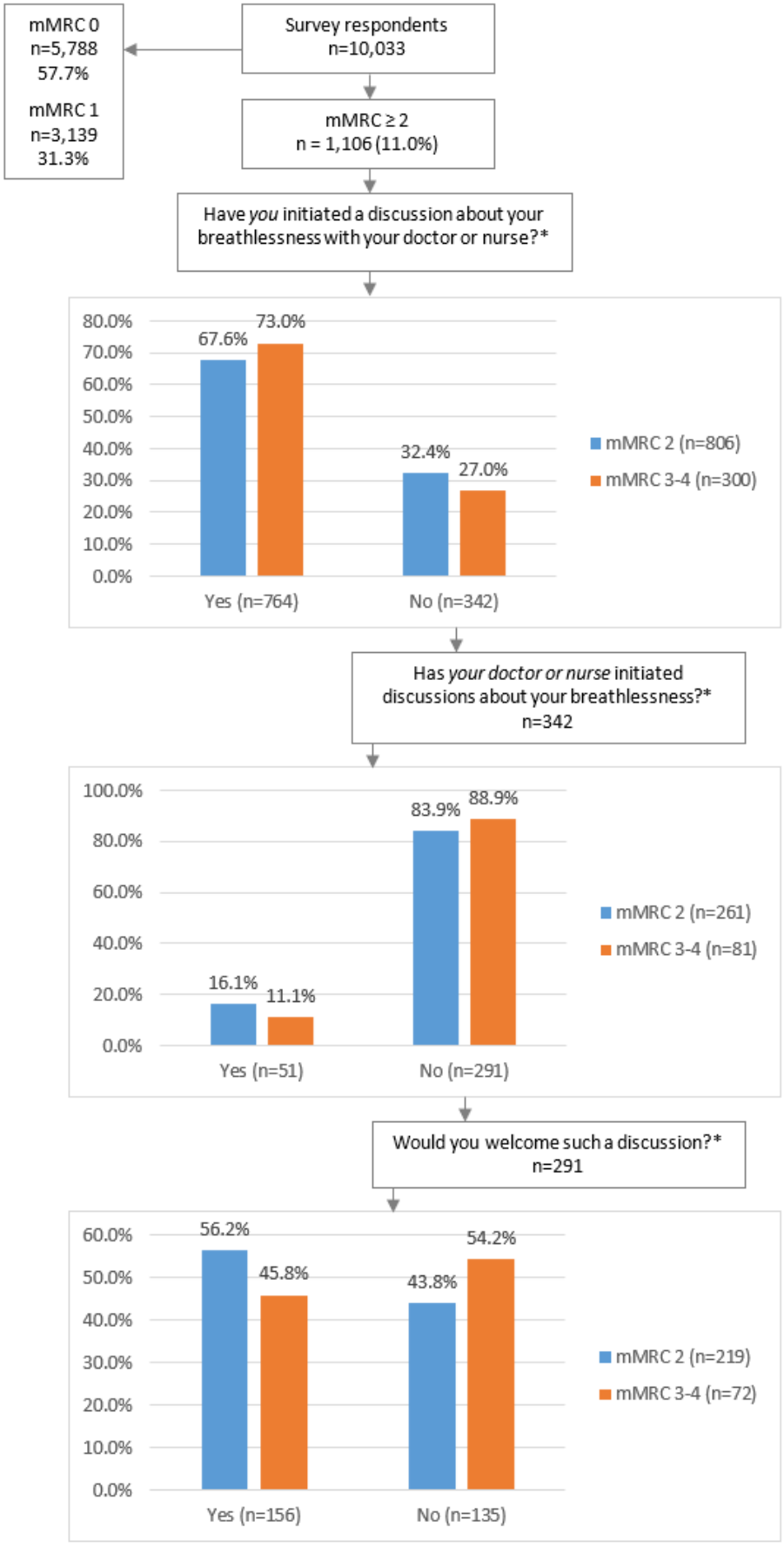
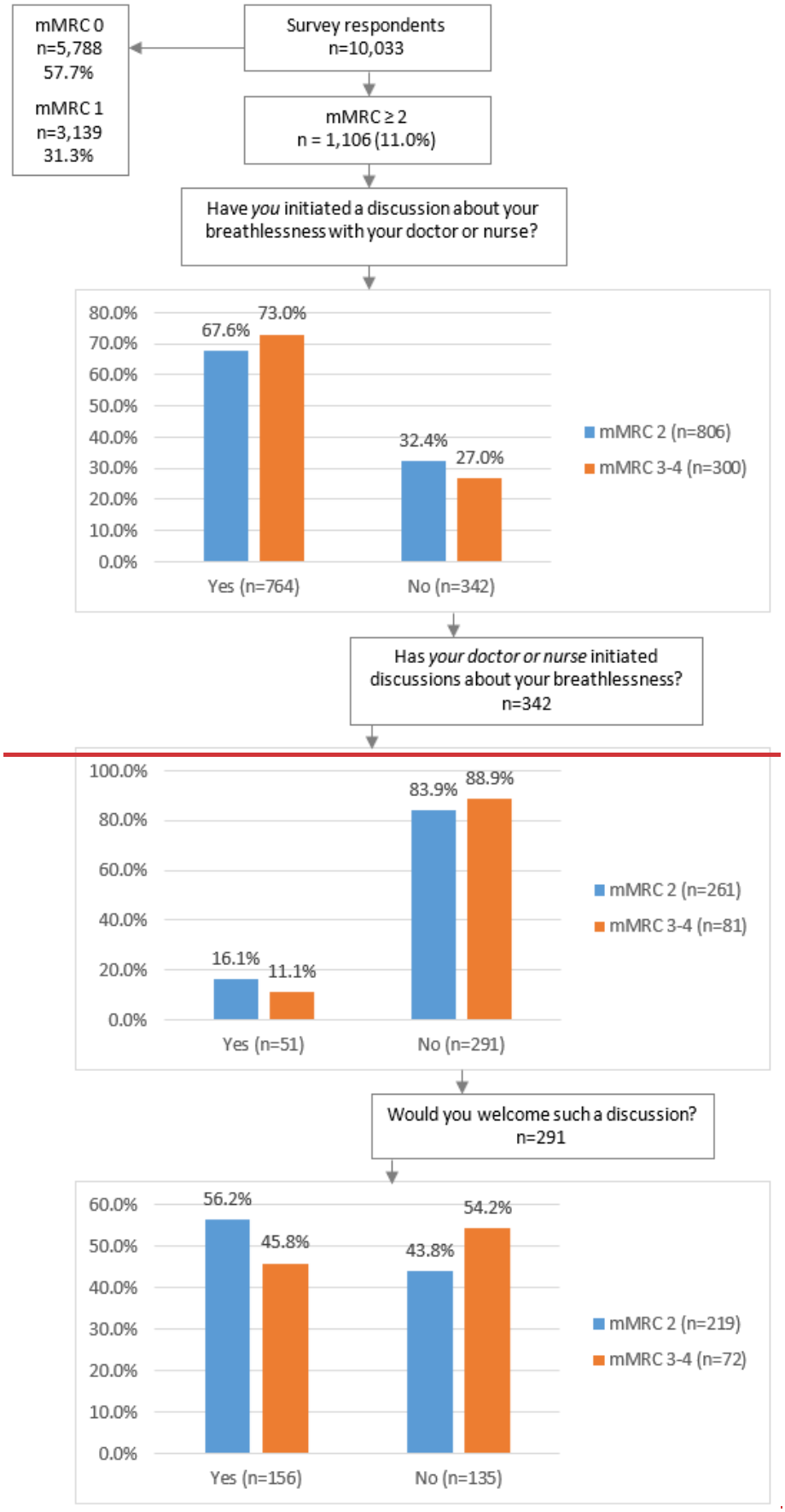


Figure 1. Survey questions and main findings. *No significant difference by intensity of breathlessness.


mMRC 0
n=5,788
57.7%
mMRC 1
n=3,139
31.3%
Survey respondents
n=10,033
mMRC ≥ 2
n = 1,106 (11.0%)
Have *you* initiated a discussion about your breathlessness with your doctor or nurse?
80.0%
70.0%
60.0%
50.0%
40.0%
30.0%
20.0%
10.0%
0.0%
67.6%
73.0%
32.4%
27.0%
Yes (n=764)
No (n=342)
mMRC 2 (n=806)
mMRC 3-4 (n=300)
Has *your doctor or nurse* initiated discussions about your breathlessness?
n=342
100.0%
80.0%
60.0%
40.0%
20.0%
0.0%
16.1%
11.1%
83.9%
88.9%
Yes (n=51)
No (n=291)
mMRC 2 (n=261)
mMRC 3-4 (n=81)
Would you welcome such a discussion?
n=291
60.0%
50.0%
40.0%
30.0%
20.0%
10.0%
0.0%
56.2%
45.8%
43.8%
54.2%
Yes (n=156)
No (n=135)
mMRC 2 (n=219)
mMRC 3-4 (n=72)

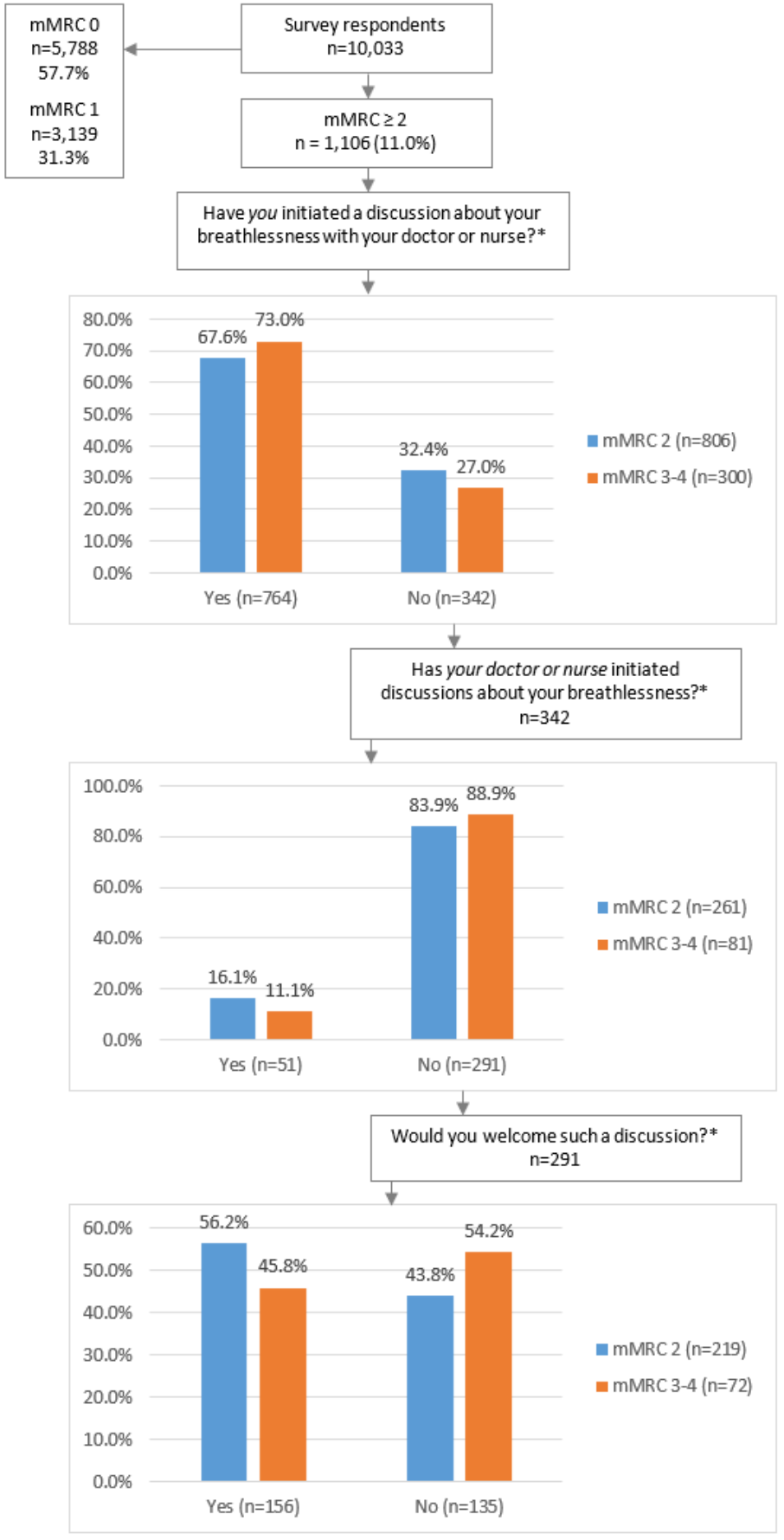


Figure 1. Survey questions and main findings. *No significant difference by intensity of ~~persistent~~ breathlessness.