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‘A balancing act’. Living with severe chronic obstructive pulmonary disease in Southern New Zealand: a qualitative study

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Supplementary Table S1. COPD study - Patient Interview Topic Guide (probe questions in grey)

Question
<p>What can you tell me about your condition?</p> <p>Who explained the condition to you when you were first told you had COPD? May want to then ask, "How was that for you?"</p> <p>What kind of information were you given? May need to be more specific here as they may say verbal or written or may discuss the topic areas of the information provided. We need to decide what it is we want information on.</p> <p>Was the condition, treatment options, and prognosis explained to you in a way you understood? Did you feel you had the information you needed to understand your situation and make any necessary decisions? Was there anything you didn't understand?</p> <p>Was the diagnosis given in an understanding and considerate manner?</p> <p>Do you have any other condition(s) and did you have these before your diagnosis or after?</p>
<p>Could you tell me about how having COPD has impacted on your life?</p> <p>At this stage of your condition, what does a good day look like? (Explore)</p> <p>At this stage of your condition, what does a bad day look like? (Explore)</p> <p>Have you had to make any adaptations to your life as your condition has progressed? (Depending on the person and their situation, this question will be probed around...)</p> <ul style="list-style-type: none"> - Do these include changes to things you do physically? - Do these include changes to your social life/friendships/relationships with others? - Do these include changes to the way you think about yourself? - Do these include changes to the way you manage your feelings? - Do these include changes to things that you can manage shopping lists, or banking, etc. <p>What do you value in your life? What is important to you generally? or What matters to you most these days?</p>
<p>Could you tell me about the health and social care services you use?</p> <p>What health professionals do you see regularly?</p> <p>How many different health professionals are involved in your care? How do you feel about the number of health professionals involved in your care? Is there a particular health professional that you feel supports you or do you feel the team of professionals provide support?</p> <p>Do you receive any social support or access social services now that you have COPD?</p>
<p>Can you tell me about how you manage your illness?</p> <p>How do you feel you cope with symptom management?</p> <p>Do you set yourself goals and work towards them in relation to your disease?</p> <p>Do you know if there are ways to avoid exacerbations?</p> <p>Do you know how to manage exacerbations when they occur?</p>
<p>How do you feel about the communication between yourself and people within your health care team?</p> <p>When you have spoken to health professionals about your condition, symptoms or home situation, do you feel they have understood and cared about what you have said?</p> <p>Have you had an appointment or health visit, where you have felt confused or you wanted more information than was provided?</p>

Do you feel that people judge or discriminate against you because you have COPD (or for any other reason)?

Have you had discussions with your health professionals and/or family about planning for the future?

Have you talked about what medical treatments you may need in the future (and with whom? When?)

How much do you want to know?

How involved do you want to be in your treatment decisions in the future? How involved do you want your loved ones to be?

What have people (either health or social service professional or partner/family/friend) done for you that has been particularly helpful?

Why was it helpful –why does that stand out for you?

What do people (either health or social service professional or partner/family/friend, etc.) understand least about your condition and situation?

Why do you think that is?

What top three tips would you give to someone who has newly been diagnosed with COPD?

(Clarify answer to make sure the meaning of them has been understood)