<table>
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<th>Theme</th>
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| **Isolation**            | • “I was on the outside of any social group or gathering and on the inside, I was very alone and depressed and isolated and very frightened”  
• “I realized that something was "wrong" with me, and didn’t know what, and it looked like nobody knew. I more or less expected to have a unique disease which would have my name.”  
• “I’ve pretty much been in exile for the past ten years”  
• (the hardest part of CHH) “The body image problems really... I will have that until the day I die”  
• “I can’t get undressed... I haven’t been swimming in many years. I can’t even pull my sleeves up... I can’t sit there like you with your sleeves rolled up...I’ve got to keep covered.”  
• “I have a tough time engaging with people, talking with people. Usually, when I am out in public I tend to look down at the ground, because you know... I feel so ashamed”  
• “I always thought there was a big spotlight on me all the time. Just... self-conscious... absolutely. I got a lot of bullying and being pushed around and abused when I was young”  
• “I’m 40 years old and should be at the prime of my career and I don’t see myself… I don’t know, it’s a psychological barrier that I can’t progress, I’m stuck”  
• “For Kallmann’s (CHH), it’s sort of a crucial sort of time you know, we say the psychological and emotional things are equally as big as the medical forms of treatment for it. That big, big thing (absent puberty) carries on for the rest of your life”  
• “I have depression, definitely. I have noticed a common denominator with depression and self medication... myself included”  
• “…and my family, they weren’t supportive. They didn’t help me. So, I got depressed and I tried to take my own life and then um…I left to seek help on my own” | connecting with others & peer-to-peer support                                                                                                                                                                                                                                                                                                                                 |                                                                                                                                                                                                                                                  |
| **Shame**                | • i. body image  
• “I can’t get undressed... I haven’t been swimming in many years. I can’t even pull my sleeves up... I can’t sit there like you with your sleeves rolled up...I’ve got to keep covered.”  
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| cognitive-behavioral interventions                                                                                                                                                                                                                                                                                                                                 |                                                                                                                                                                                                                                                  |
|                         | • ii. self-esteem  
• “I always thought there was a big spotlight on me all the time. Just... self-conscious... absolutely. I got a lot of bullying and being pushed around and abused when I was young”  
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|                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                  |
|                         | • iii. left behind  
• “I’m 40 years old and should be at the prime of my career and I don’t see myself… I don’t know, it’s a psychological barrier that I can’t progress, I’m stuck”  
• “For Kallmann’s (CHH), it’s sort of a crucial sort of time you know, we say the psychological and emotional things are equally as big as the medical forms of treatment for it. That big, big thing (absent puberty) carries on for the rest of your life”  
|                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                  |
|                         | • iv. depression & anxiety  
• “I have depression, definitely. I have noticed a common denominator with depression and self medication... myself included”  
• “…and my family, they weren’t supportive. They didn’t help me. So, I got depressed and I tried to take my own life and then um… I left to seek help on my own”  
• “...and my family, they weren’t supportive. They didn’t help me. So, I got depressed and I tried to take my own life and then um… I left to seek help on my own”  
• “The professor (doctor) who diagnosed my condition didn’t even touch on the psychological side of things”  
• “For the first few years after it (CHH) was mentioned to me, there was nothing at all coming back from the doctors. They didn’t really tell me what I was being treated for. So it was kind of… they diagnosed me but didn’t tell me and anything”  
• “The doctors weren’t… it was just nothing. There was no real after-care at all after the diagnosis. It was just ‘you need to take these injections’ and that was that… you know, for the rest of your life. There was no kind of… nothing. It was a lack of communication really”  
• “I felt like I wasn’t considered intelligent enough to understand what I was being treated for. It was like ‘oh, you won’t understand, it’s complicated’. That’s it… yeah, it’s not nice to be made to feel that way.”  
• “Somebody once said something to me, actually it was an endocrinologist, and I said ‘but I’m not normal’ you know? And this was several years ago, and I think he was trying to say ‘look, everything will be alright, keep taking your medication and all the rest of it’ and I said ‘I don’t know what normal is’...and that didn’t seem to faze him at all. I sat there saying to this professional, educated, intelligent man—he’s a professor—and I was saying ‘I don’t know what normal is’ and he didn’t respond. Nothing… he didn’t even look at me.”  
• “There’s no sense from anyone... about them trying to understand or even that it crosses their mind that you are going through anything. You know, that it’s painful. They are just ‘Mr. fix-it’ - give you a prescription and you are gone”  
| online information & resources                                                                                                                                                                                                                                                                                                                                 |                                                                                                                                                                                                                                                  |
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| promoting patient-centered approaches & developing a “talking sheet” to initiate discussions with providers                                                                                                                                                                                                 |                                                                                                                                                                                                                                                  |
|                         | • disregard for feelings  
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• “There’s no sense from anyone... about them trying to understand or even that it crosses their mind that you are going through anything. You know, that it’s painful. They are just ‘Mr. fix-it’ - give you a prescription and you are gone”  
• “The doctors didn’t give me any treatment options. He just said ‘take this gel’. We didn’t discuss what was the best treatment. I don’t know if it was just the physician that I went to... maybe there are better ones out there who would have given me the option(s)”  
| lack of shared decision-making                                                                                                                                                                                                                                                                                                                                 |                                                                                                                                                                                                                                                  |
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| online anticipatory guidance information                                                                                                                                                                                                                                                                                                                                 |                                                                                                                                                                                                                                                  |
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| negative healthcare interactions                                                                                                                                                                                                                                                                                                                                 |                                                                                                                                                                                                                                                  |
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|                         | • “The first doctor I saw he said just take these and you’ll be ok”  
• “He (doctor) didn’t give me any treatment options. He just said ‘take this gel’. We didn’t discuss what was the best treatment. I don’t know if it was just the physician that I went to... maybe there are better ones out there who would have given me the option(s)”  
|                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                  |
|                         | • “No one really explained to me... I thought that if I took the testosterone...I didn’t understand that...I thought that if I just took the testosterone that I would go through puberty and I would be normal.”  
• “I said no, I can’t smell a thing adn he said, ‘Ah, you’ve got Kallmann’s (CHH)! I thought wow that’s great, give me the injections and I can smell the roses and all that and well of course it didn’t happen. My sense of smell never came.”  
|                                                                                                                                                                                                                              |                                                                                                                                                                                                                                                  |

* Quotes referencing the term “Kallmann’s” refers to Kallmann syndrome - the association of CHH with the inability to smell (anosmia)