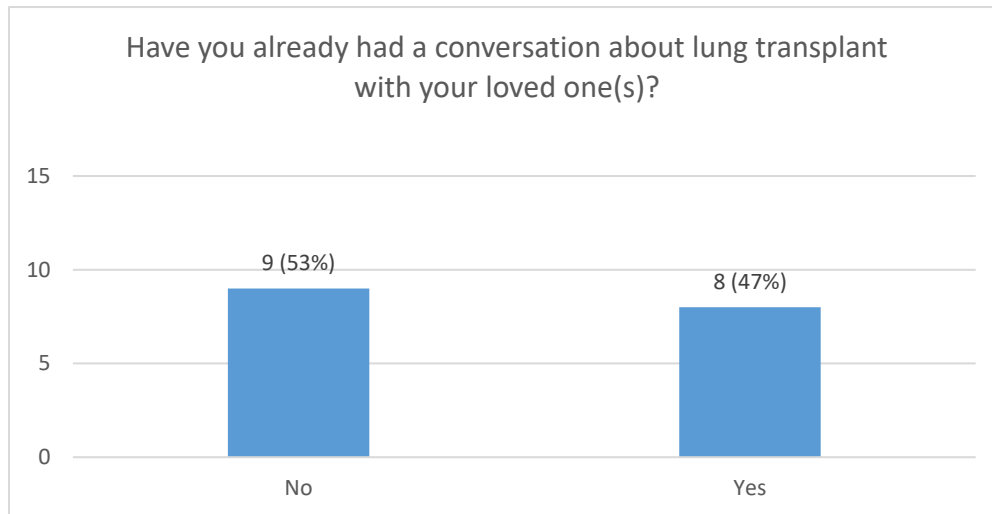
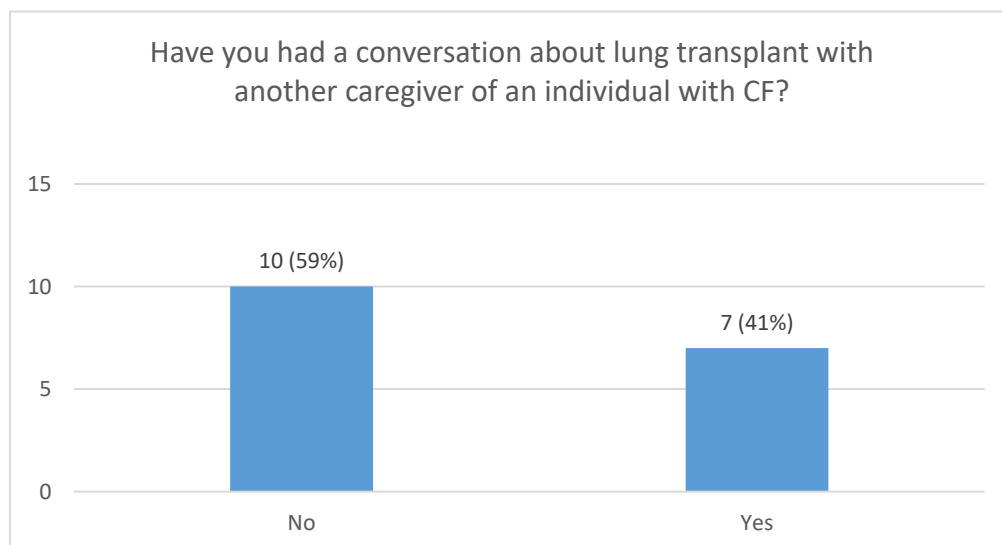


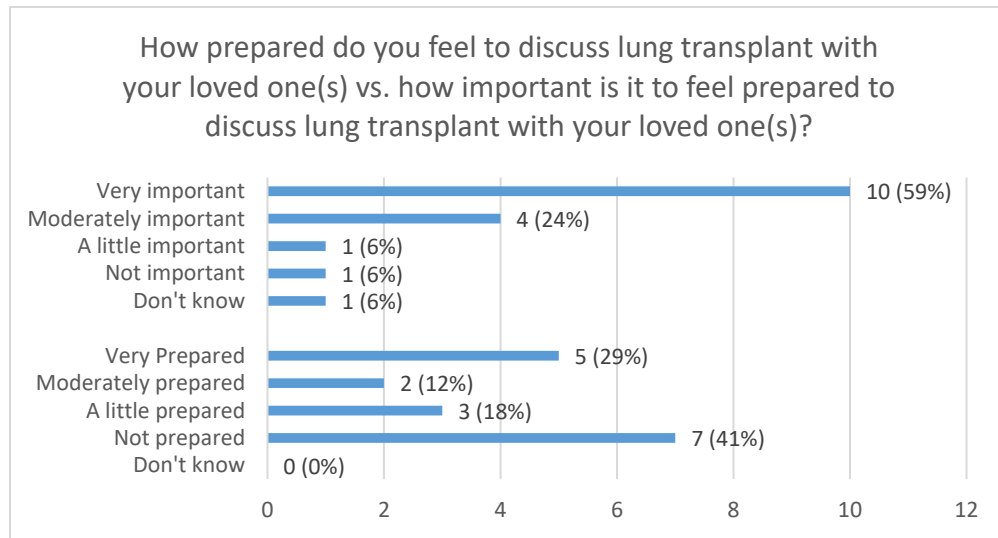
Researchers at the University of Washington distributed a survey to Community Voice caregivers of individuals with CF that aimed to understand their lung transplant information needs. Of the 21 responses received, the following was found:



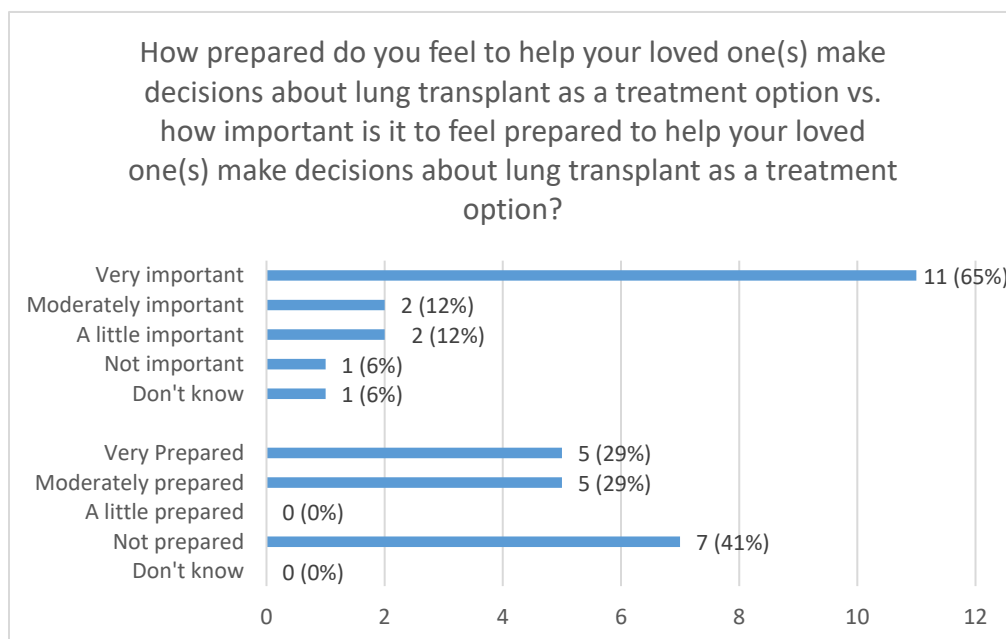
More than half of the respondents who are caregivers for individuals with CF and have not received a lung transplant reported not talking to their loved one(s) about lung transplant as a treatment option previously.



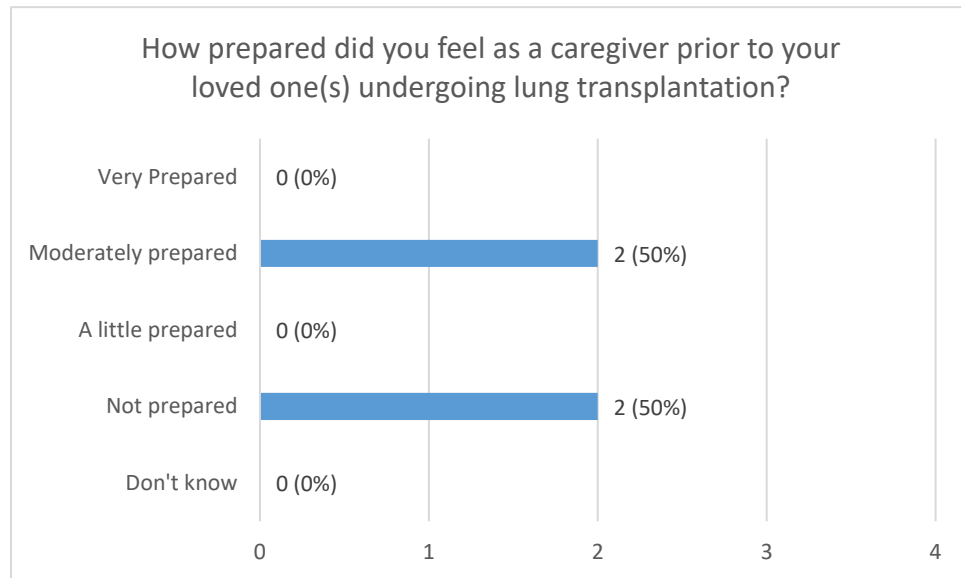
Similarly, more than half of the respondents who are caregivers for individuals with CF and have not received a lung transplant reported not talking to a caregiver of another individual with CF about lung transplant previously.



When asked how prepared these respondents felt discussing lung transplant with their loved one(s), only 29% felt they were very prepared. However, when asked how important it is to feel prepared to discuss lung transplant with their loved one(s), 59% agreed that it is very important to feel prepared.



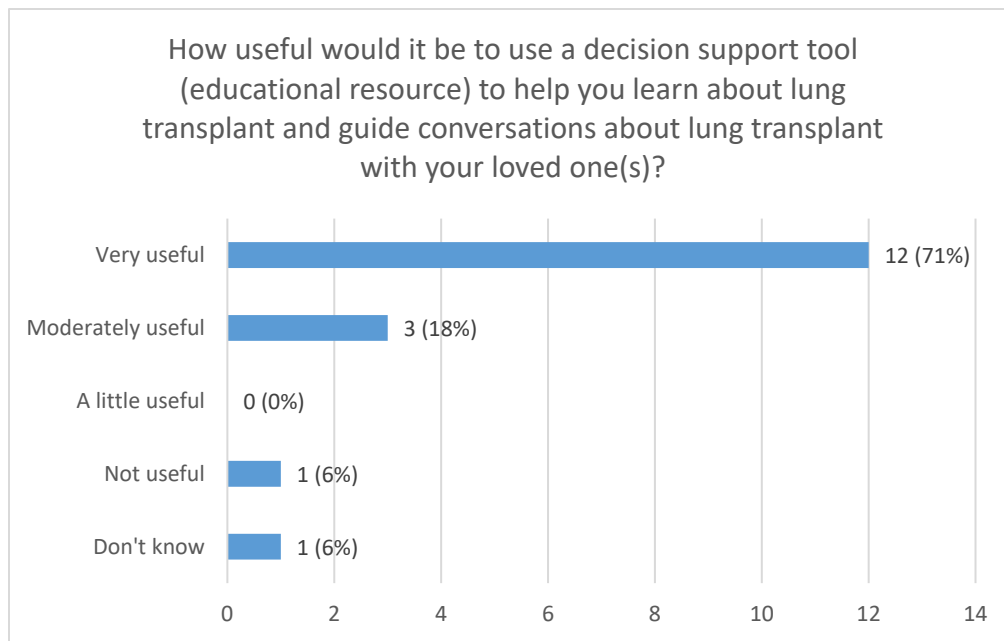
Similarly, when asked how prepared these respondents felt in helping their loved one(s) make decisions about lung transplant as a treatment option only 29% felt they were very prepared. However, when asked how important it is to feel prepared to help their loved one(s) make decisions about lung transplant as a treatment option, 65% agreed that it is very important to feel prepared.



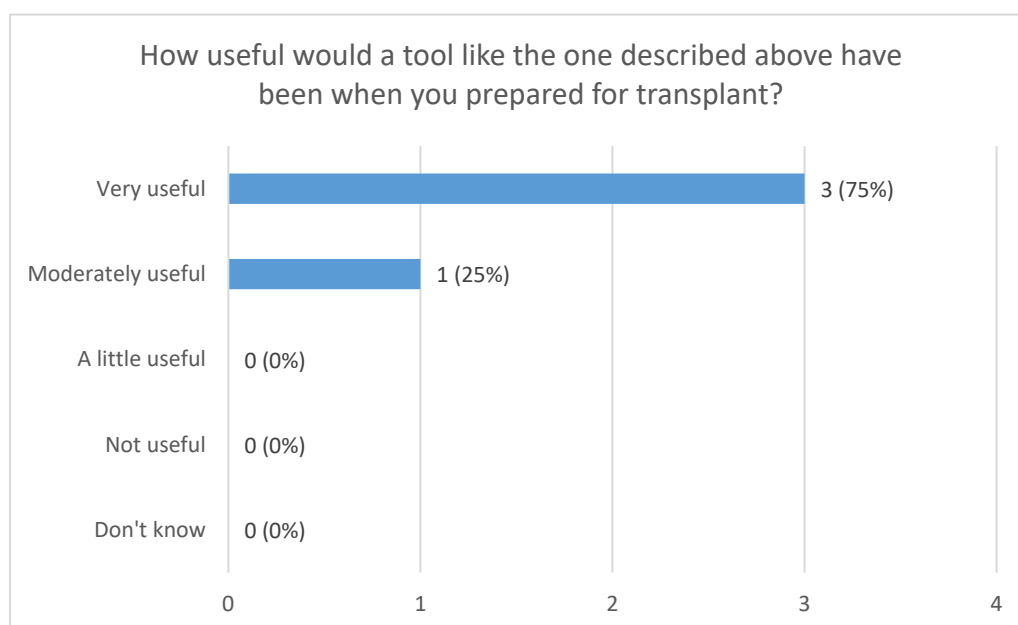
Of the respondents who are caregivers for individuals with CF who have received lung transplants, 50% stated that they were not prepared prior to their loved one(s) receiving a lung transplant and 0% felt very prepared.

These gaps in preparedness for having discussions with loved one(s), helping loved one(s) in decision-making, and caregiver responsibilities present an opportunity to help caregivers as they navigate lung transplant with their loved one(s).

Researchers at the University of Washington have developed a lung transplant decision support tool that aims to help patients have conversations with their doctor about lung transplant and make informed decisions about lung transplant. However, with CF-specific lung transplant information and caregiver information, this tool could also be helpful for caregivers going through the process with loved one(s).



Of the respondents who are caregivers for individuals with CF and have not received a lung transplant, 71% agree that a lung transplant decision support tool would be very useful for learning about lung transplant and guiding future conversations.



Of the respondents who are caregivers for individuals with CF who have received lung transplants, 75% agree that a lung transplant decision support tool with CF-specific educational content and caregiver information would have been very useful in helping them prepare for transplant.