Table 1 Demographic characteristics of the participants (n = 50)

Characteristic	No.	Patient number	%
Age (years)			
< 60	5	P8, P26, P27, P28, P34	10
60–69	15	P3, P4, P6, P15, P17, P18, P19, P21, P24, P25, P32, P36, P44, P46, P47	30
70–80	23	P1, P2, P5,P7, P10, P12, P13, P16, P20, P22, P23, P29, P30, P31, P33, P35, P37, P38, P40, P41, P43, P48, P50	46
> 80	7	P9, P11, P14, P39, P42, P45, P49	14
Sex			
Male	28	P1, P4, P5, P6, P7, P9, P13, P16. P18, P19, P20, P21, P22, P23, P24, P26, P27, P29, P30, P31, P32, P36, P37, P40, P41, P42, P43, P50	56
Female	22	P2, P3, P8, P10, P11, P12, P14, P15, P17, P25, P28, P33, P34, P35, P38, P39, P44, P45, P46, P47, P48, P49	44
Disease severity			
Mild	6	P13, P17, P18, P20, P22, P28	12
Moderate	20	P4, P6, P12, P15, P16, P19, P23, P25, P26, P29, P30, P31, P34, P35, P36, P38, P39, P44, P46, P47	40
Severe	10	P7, P9, P10, P11, P27, P33, P37, P40, P42, P45	20
Very severe	14	P1, P2, P3, P5, P8, P14, P21, P24, P32, P41, P43, P48, P49, P50	28
Age at diagnosis (years)			
< 5	24	P1, P6, P13, P14, P15, P17, P18, P19, P20, P25, P26, P28, P30, P32, P33, P34, P35, P36, P27, P28, P29, P40, P44, P47	48
5–9	19	P2, P3, P4, P5, P8, P9, P12, P16, P24, P27, P29, P31, P41, P43, P45, P46, P48, P49, P50	38
> 10	7	P7, P10, P11, P21, P22, P23, P42	14
Caregiver			
Family member	34	P1, P4, P6, P7, P9, P11, P12, P14, P16, P18, P19, P20, P21, P23, P24, P25, P27, P29, P30, P31, P32, P33, P36, P37, P39, P40, P41, P42, P43, P44, P45, P48, P49, P50	68
Non-family member	8	P2, P3, P5, P8, P10, P34, P35, P38	16
Without help	8	P13, P15, P17, P22, P26, P28, P46, P47	16
Current work			
Yes	15	P4,P6, P8, P18, P19, P22, P26, P30, P34, P36, P40, P42, P46, P48, P49	30
No	35	P1, P2, P3, P5, P7, P9, P10, P11, P12, P13, P14, P15, P16, P17, P20, P21, P23, P24, P25, P27, P28, P29, P31, P32, P33, P35, P37, P38, P39, P41, P43, P44, P45, P47, P50	70