

**#R code for dataset "ENTWINE_ESR14_Kidney Carer Survey Data_2022-08_30" and
"ENTWINE_ESR14_Kidney Carer Survey_Clean DASS-21_2022-08-30"**

#Dataset "ENTWINE_ESR14_Kidney Carer Survey Data_2022-08_30" contains raw DASS-21 data

**#Dataset "ENTWINE_ESR14_Kidney Carer Survey_Clean DASS-21_2022-08-30" contains cleaned
DASS-21 data, with imputed values for participants missing 1 value per sub-scale.**

**#Dataset "ENTWINE_ESR14_Kidney Carer Survey_Clean DASS-21_2022-08-30" is used for the
analysis of DASS-21 data**

**#Key linking question numbers to survey questions for both datasets is in file
"ENTWINE_ESR14_Kidney Carer Survey_KEY_2022-08-30"**

#Data corresponds to manuscript:

##Coumoundouros, C., Farrand, P., Hamilton, A., von Essen, L., Sanderman, R., & Woodford, J.

**##Cognitive behavioural therapy self-help intervention preferences among informal caregivers of
adults with chronic kidney disease: an online cross-sectional survey.**

#Code prepared by Chelsea Coumoundouros

#August 30, 2022

**#Dataset "ENTWINE_ESR14_Kidney Carer Survey Data_2022-08_30" should import as a dataset
with 65 observations of 99 variables**

**#Dataset "ENTWINE_ESR14_Kidney Carer Survey_Clean DASS-21_2022-08-30" should import as a
dataset with 65 observations of 21 variables**

**#Note: Data collected on first half of participant's postal code has been removed from dataset to
ensure participant anonymity.**

##Note: questions that allowed participants to SELECT ALL THAT APPLY were analyzed manually

#USE DATASET "ENTWINE_ESR14_Kidney Carer Survey Data_2022-08_30"

#IMPORT DATASET AS data

#age

mean(data\$Q9)

```
sd(data$Q9)
```

```
median(data$Q9)
```

```
IQR(data$Q9)
```

```
min(data$Q9)
```

```
max(data$Q9)
```

```
#gender
```

```
table<-table(data$Q10)
```

```
table
```

```
prop.table(table)
```

```
#location (country)
```

```
table2<-table(data$Q18)
```

```
table2
```

```
prop.table(table(data$Q18))
```

```
#ethnic group
```

```
prop.table(table(data$Q21))
```

```
table(data$Q21)
```

```
#relationship status
```

```
prop.table(table(data$Q22))
```

```
table(data$Q22)
```

```
#number of kids needing support
```

```
mean(data$Q23, na.rm = T)
```

```
sd(data$Q23, na.rm=T)
```

```
table(data$Q23)
```

```
prop.table(table(data$Q23))
```

```
#employment status
```

```
prop.table(table(data$Q24))
```

```
table(data$Q24)
```

```
#education
```

```
#FOR RECODING BASED ON ISCED LEVELS
```

```
##Apprenticeship is Level 3
```

```
##A level is Level 3
```

```
##Bachelors or higher is ISCED Level 6+
```

```
##Foundation degree etc is Level 5
```

```
##GCSEs is Level 3
```

```
##NVQ1-2 etc is Level 3
```

```
prop.table(table(data$Q25))
```

```
table(data$Q25)
```

```
#presence of other unpaid carers
```

```
prop.table(table(data$Q32))
```

```
table(data$Q32)
```

```
#presence of formal care in home
```

```
prop.table(table(data$Q33))
```

```
table(data$Q33)
```

```
#receiving carers allowance
```

```
prop.table(table(data$Q34))
```

```
table(data$Q34)
```

```
#Time caring
```

```
##convert years in Q30_1 to months by multiplying by 12
```

```
##note one participant did not respond
```

```
data$Q30_1_months<-data$Q30_1
```

```
print(data$Q30_1_months)
```

```
print(data$Q30_1)
```

```
data$Q30_1_months<-data$Q30_1_months*12
```

```
print(data$Q30_1_months)
```

```
##Setting NA in Q30_2 to value of 0 so that Q30_2 can be added to Q30_1_months to get total  
months caregiving
```

```
data$Q30_2[is.na(data$Q30_2)]<- 0
```

```
data$Q30_TOTALMONTHS<-data$Q30_1_months+data$Q30_2
```

```
print(data$Q30_TOTALMONTHS)
```

```
##Mean and SD total months providing care
```

```
mean(data$Q30_TOTALMONTHS, na.rm = T)
```

```
sd(data$Q30_TOTALMONTHS, na.rm = T)
```

```
##for Mean and SD for total YEARS providing care
```

```
data$Q30_TOTALYEARS<-data$Q30_TOTALMONTHS
```

```
data$Q30_TOTALYEARS<-data$Q30_TOTALYEARS/12
```

```
print(data$Q30_TOTALYEARS)
```

```
mean(data$Q30_TOTALYEARS, na.rm = T)
```

```
sd(data$Q30_TOTALYEARS, na.rm = T)
```

```
median(data$Q30_TOTALYEARS, na.rm = T)
```

```
min(data$Q30_TOTALYEARS, na.rm = T)
```

```
max(data$Q30_TOTALYEARS, na.rm = T)
```

```
IQR(data$Q30_TOTALYEARS, na.rm = T)
```

```
#How well they are coping
```

```
prop.table(table(data$Q29))  
table(data$Q29)
```

```
#age CARE RECIPIENT  
mean(data$Q36, na.rm = T)  
sd(data$Q36, na.rm = T)  
min(data$Q36, na.rm = T)  
max(data$Q36, na.rm = T)  
median(data$Q36, na.rm = T)  
IQR(data$Q36, na.rm = T)
```

```
#gender CARE RECIPIENT  
table3<-table(data$Q37)  
prop.table(table3)  
table3
```

```
#Caregiver relation to Care recipient  
prop.table(table(data$Q38))  
table(data$Q38)
```

```
#living with CARE RECIPIENT  
prop.table(table(data$Q39))  
table(data$Q39)
```

```
#distance from CARE RECIPIENT in miles  
mean(data$Q40_1, na.rm = T)  
sd(data$Q40_1, na.rm = T)
```

```
#time to travel to CARE RECIPIENT minutes
```

#values not understood as numeric in R. Can get average manually as very few input any value here

#how often they see the CARE RECIPIENT

prop.table(table(data\$Q41))

table(data\$Q41)

##for date of diagnosis

##for caregivers that did not specify a month - we assume month 06 (JUNE) as mid-point in the year

##base calculations based on current reference time of 01-09-2022 (SEPTEMBER 1, 2022)

#manual calculation done in Excel

#Care recipient terminally ill?

prop.table(table(data\$Q48))

table(data\$Q48)

#Number of co-morbid conditions

prop.table(table(data\$Q49))

table(data\$Q49)

##INTERVENTION SECTION OF SURVEY

#likelihood they would use a self-help program

prop.table(table(data\$Q52))

table(data\$Q52)

#####remember that people who indicate "extremely unlikely" go straight to DASS-21 section

#have they sought help before

prop.table(table(data\$Q53))

table(data\$Q53)

##FORMAT PREFERENCES

#audio

```
prop.table(table(data$Q54_1))
```

```
table(data$Q54_1)
```

#internet

```
prop.table(table(data$Q54_2))
```

```
table(data$Q54_2)
```

#in person, individual

```
prop.table(table(data$Q54_3))
```

```
table(data$Q54_3)
```

#in person, group

```
prop.table(table(data$Q54_4))
```

```
table(data$Q54_4)
```

#mobile app

```
prop.table(table(data$Q54_5))
```

```
table(data$Q54_5)
```

#telephone

```
prop.table(table(data$Q54_6))
```

```
table(data$Q54_6)
```

#video-call

```
prop.table(table(data$Q54_7))
```

```
table(data$Q54_7)
```

#booklet

```
prop.table(table(data$Q54_8))
```

```
table(data$Q54_8)
```

```
#when to receive information about intervention
```

```
prop.table(table(data$Q55))
```

```
table(data$Q55)
```

```
#when to start using intervention
```

```
prop.table(table(data$Q57))
```

```
table(data$Q57)
```

```
#who they want to work on intervention with
```

```
prop.table(table(data$Q58))
```

```
table(data$Q58)
```

```
#how content should be made available
```

```
prop.table(table(data$Q59))
```

```
table(data$Q59)
```

```
##TOPICS OF INTEREST
```

```
#relaxation strategies
```

```
prop.table(table(data$Q62_1))
```

```
table(data$Q62_1)
```

```
#asking/refusing help
```

```
prop.table(table(data$Q62_2))
```

```
table(data$Q62_2)
```

```
#communicating with CR
```

```
prop.table(table(data$Q62_3))
```

```
table(data$Q62_3)
```


#communicating with children/young people

```
prop.table(table(data$Q62_4))
```

```
table(data$Q62_4)
```

#communicating with care provider

```
prop.table(table(data$Q62_5))
```

```
table(data$Q62_5)
```

#communicating with boss

```
prop.table(table(data$Q62_6))
```

```
table(data$Q62_6)
```

#discussion form with caregivers

```
prop.table(table(data$Q62_7))
```

```
table(data$Q62_7)
```

#information about support services

```
prop.table(table(data$Q62_8))
```

```
table(data$Q62_8)
```

#information about physical health

```
prop.table(table(data$Q62_9))
```

```
table(data$Q62_9)
```

#information about diet

```
prop.table(table(data$Q62_10))
```

```
table(data$Q62_10)
```

#information on sex and intimacy

```
prop.table(table(data$Q62_11))
```

```
table(data$Q62_11)
```

#information about living with kidney conditions

prop.table(table(data\$Q62_12))

table(data\$Q62_12)

#information on end of life and grief

prop.table(table(data\$Q62_13))

table(data\$Q62_13)

#QUESTIONS ABOUT HAVING SUPPORT DURING INTERVENTION

#do they want support

prop.table(table(data\$Q65))

table(data\$Q65)

####remember if they say NO support, they are brought to open text box for other comments and DASS21

##FORMAT OF SUPPORT

#automatic email or sms

prop.table(table(data\$Q66_1))

table(data\$Q66_1)

#personal email

prop.table(table(data\$Q66_2))

table(data\$Q66_2)

#sms

prop.table(table(data\$Q66_3))

table(data\$Q66_3)

#in person

```
prop.table(table(data$Q66_4))
```

```
table(data$Q66_4)
```

```
#telephone
```

```
prop.table(table(data$Q66_5))
```

```
table(data$Q66_5)
```

```
#video-call
```

```
prop.table(table(data$Q66_6))
```

```
table(data$Q66_6)
```

```
#location of support if in-person
```

```
prop.table(table(data$Q67))
```

```
table(data$Q67)
```

```
#who provides support
```

```
prop.table(table(data$Q68))
```

```
table(data$Q68)
```

##DASS-21 Scoring

```
#USE DATASET "ENTWINE_ESR14_Kidney Carer Survey_Clean DASS-21_2022-08-30"
```

```
#IMPORT DATASET AS dass21
```

##IMPUTATION & MISSING DATA

#Participants missing one value PER SUBSCALE were included in the analysis. Participants missing more than one value PER SUBSCALE were excluded from the analysis of that subscale.

#The missing value was imputed from the average score of the non-missing values in the scale. Cells with imputation are highlighted in the Excel file.

#For the DEPRESSION Subscale, 1 value total was imputed (i.e. 1 participant had a missing value). 1 participant was excluded from the analysis due to missing data.

#For the ANXIETY Subscale, 1 value total was imputed (i.e. 1 participant had a missing value). 1 participant was excluded from the analysis due to missing data.

#For the STRESS Subscale, 3 values total were imputed (i.e. 3 participants had a missing value).

##SUM FOR EACH SUBSCALE

```
dass21$Q51_DEPRESSION<-  
dass21$Q51_3+dass21$Q51_5+dass21$Q51_10+dass21$Q51_13+dass21$Q51_16+dass21$Q51_17+  
dass21$Q51_21
```

```
dass21$Q51_Anxiety<-  
dass21$Q51_2+dass21$Q51_4+dass21$Q51_7+dass21$Q51_9+dass21$Q51_15+dass21$Q51_19+da  
ss21$Q51_20
```

```
dass21$Q51_Stress<-  
dass21$Q51_1+dass21$Q51_6+dass21$Q51_8+dass21$Q51_11+dass21$Q51_12+dass21$Q51_14+d  
ass21$Q51_18
```

#MULTIPLE EACH SUBSCALE SUM BY 2 FOR FINAL SCORES

```
dass21$Q51_DEPRESSION<-dass21$Q51_DEPRESSION*2
```

```
dass21$Q51_Anxiety<-dass21$Q51_Anxiety*2
```

```
dass21$Q51_Stress<-dass21$Q51_Stress*2
```

##Mean and SD FOR DASS-21 SCORES

```
mean(dass21$Q51_DEPRESSION, na.rm = T)
```

```
sd(dass21$Q51_DEPRESSION, na.rm = T)
```

```
mean(dass21$Q51_Anxiety, na.rm = T)
```

```
sd(dass21$Q51_Anxiety, na.rm = T)
```

```
mean(dass21$Q51_Stress, na.rm = T)
```

```
sd(dass21$Q51_Stress, na.rm = T)
```

#Categories

```
dass21$Q51_Stress_CAT_TEST[dass21$Q51_Stress >= 0 & dass21$Q51_Stress <= 14] <- "normal"
dass21$Q51_Stress_CAT_TEST[dass21$Q51_Stress >= 15 & dass21$Q51_Stress <= 18] <- "mild"
dass21$Q51_Stress_CAT_TEST[dass21$Q51_Stress >= 19 & dass21$Q51_Stress <= 25] <- "moderate"
dass21$Q51_Stress_CAT_TEST[dass21$Q51_Stress >= 25.5 & dass21$Q51_Stress <= 33] <- "severe"

#Notes: one participants score was 25.7 and R would not categorize when severe category was 26-
33. As 25.7 would round up to 26, it would be counted as severe. Adjustment of category range for
sever accounted for this.

dass21$Q51_Stress_CAT_TEST[dass21$Q51_Stress >= 34] <- "extremely severe"
```

```
dass21$Q51_Anxiety_CAT[dass21$Q51_Anxiety <= 7] <- "normal"
dass21$Q51_Anxiety_CAT[dass21$Q51_Anxiety >= 8 & dass21$Q51_Anxiety < 10] <- "mild"
dass21$Q51_Anxiety_CAT[dass21$Q51_Anxiety >= 10 & dass21$Q51_Anxiety < 15] <- "moderate"
dass21$Q51_Anxiety_CAT[dass21$Q51_Anxiety >= 15 & dass21$Q51_Anxiety < 19] <- "severe"
dass21$Q51_Anxiety_CAT[dass21$Q51_Anxiety >= 20 & dass21$Q51_Anxiety < 130] <- "extremely
severe"
```

```
dass21$Q51_DEPRESSION_CAT[dass21$Q51_DEPRESSION <= 9] <- "normal"
dass21$Q51_DEPRESSION_CAT[dass21$Q51_DEPRESSION >= 10 & dass21$Q51_DEPRESSION < 14] <-
"mild"
dass21$Q51_DEPRESSION_CAT[dass21$Q51_DEPRESSION >= 14 & dass21$Q51_DEPRESSION < 21] <-
"moderate"
dass21$Q51_DEPRESSION_CAT[dass21$Q51_DEPRESSION >= 21 & dass21$Q51_DEPRESSION < 28] <-
"severe"
dass21$Q51_DEPRESSION_CAT[dass21$Q51_DEPRESSION >= 28 & dass21$Q51_DEPRESSION <
130] <- "extremely severe"
```

#proportions and frequencies of DASS-21 categories

```
table(dass21$Q51_Stress_CAT_TEST)
prop.table(table(dass21$Q51_Stress_CAT_TEST))
```

```
table(dass21$Q51_DEPRESSION_CAT)
prop.table(table(dass21$Q51_DEPRESSION_CAT))
```

```
table(dass21$Q51_Anxiety_CAT)
prop.table(table(dass21$Q51_Anxiety_CAT))
```

##Notes on manual analyses

#Q about who else (if anyone) they care for

#One participant said they care for themselves - I coded this as if they said NO because everyone may be caring for themselves.

#For question about what activities they provide informal care for

##Two participants who selected OTHER were not counted as they were more comments rather than an activity they provide care for (one was feeling guilty if CR cleans, one was just mentioned the CR now had a transplant)

#TYPE OF TREATMENT

##Four participants who selected OTHER for a type of treatment the care recipient receives, were re-coded to "Medication for the kidney condtion" (responses recoded were: post-transplant medication, immosuppressants, blood pressure medication, phosphate medication, fluid retention)