

Effect of COVID-19 on Emotional Well-being in People with Multiple Endocrine Neoplasia (MEN) Syndromes in the United Kingdom

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Introduction/Background:

In addition to prioritised research into new therapies and vaccines for COVID-19 during 2020, there has been an increasing quantity of research looking into the mental health impact of the pandemic on various populations. Pierce et al (2020)¹ found, in their longitudinal survey of the UK population (aged 16 and over), that the mental health of the UK population as a whole has deteriorated during the pandemic in contrast to 2019 data. Their findings suggest that those most at risk of mental health deterioration during the pandemic include young women living with children (especially preschool age), people living in low-income households, and people who were employed prior to the pandemic. Interestingly, they did not find that being single, unemployed, or having a pre-existing health condition putting a person at greater risk from COVID-19 was a contributor to mental distress. Conversely, other studies have found that people with pre-existing medical conditions are at greater risk of mental distress².

Therefore, during the week beginning 19 October, 2020 (prior to the 2nd lock-down in England), we ran a snapshot survey of our members with MEN to ascertain what affect, if any, the COVID-19 pandemic was having on their emotional well-being and whether there were any issues that we should urgently address as a patient support organisation. The survey was also available to those with adrenocortical cancer (ACC) and inherited pheochromocytoma and paraganglioma syndromes (PPGL), but too few responses were obtained to be able to make any analysis of these data.

Methods:

We devised a novel patient survey aimed at people with rare endocrine tumours and syndromes, incorporating a modified CORE-10 validated questionnaire. CORE-10 is used to support monitoring of change and outcomes in routine practice in psychotherapy, counselling and any other work attempting to promote psychological recovery, health and well-being. The survey ran on SurveyMonkey and was distributed by direct email to members of AMEND, as well as via public and private social media channels. Respondents were asked to agree to the terms and conditions for use of the data from the anonymous answers given. Those who did not agree were disqualified. Those answering from outside the UK were also disqualified from completing the survey. Incomplete data or disqualified status responses were not counted or analysed.

The survey asked respondents to record their feelings during their worst week of the 1st national lockdown (Week 1) and their feelings during the week beginning 12th October 2020 (Week 2). The same questions (listed below) were asked for both weeks and the possible responses to each question were 'Not at all', 'only occasionally', 'sometimes', 'often', 'most or all of the time':

1. I felt tense, anxious or nervous
2. I felt I had someone to turn to for support when needed
3. I felt able to cope when things went wrong
4. Talking to people felt too much for me
5. I felt panic or terror
6. I wished I didn't have to go on living
7. I had difficulty getting to sleep or staying asleep
8. I felt despairing and hopeless
9. I felt unhappy
10. I enjoyed the slower pace of life
11. Unwanted images or memories distressed me

Results:

A total of 90 responses were received during the week beginning 19 October, 2020. 10 responses were incomplete, 17 were disqualified, and 3 were answers from people with Inherited Paraganglioma Syndromes (too few to analyse). This left 60 complete answers for analysis from people with MEN syndromes.

Of our 60 qualifying respondents, no one described their current health as 'excellent'. 34 people described their health as either 'good' (53%) or 'very good' (3.5%), 21 as 'fair' (35%) and 5 as 'poor' (8.5%)^{Figure 1}. Most respondents were married (62%) and employed (38% full time, 20% part time) or retired (20%)^{Figure 2}. Of those working, 35% had continued working from home, 22% had continued to work outside the home, and 7% were furloughed. 49 respondents (75%) reported that their financial situation was about the same as pre-pandemic, 15% were worse off, and 10% were better off. Most respondents had no children living at home (n = 38, 63%).

Figure 1.

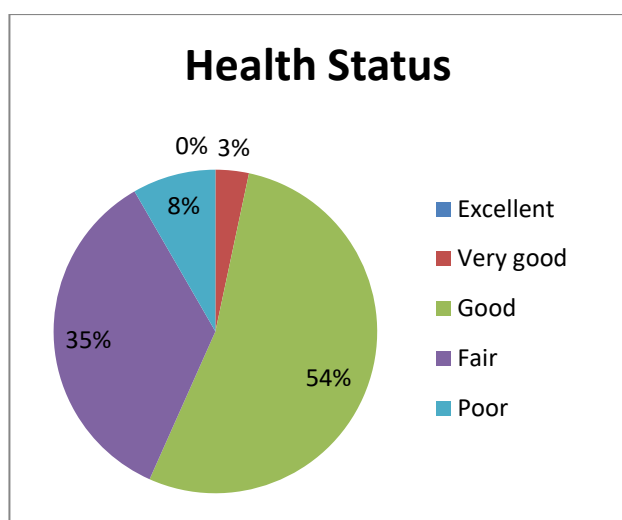
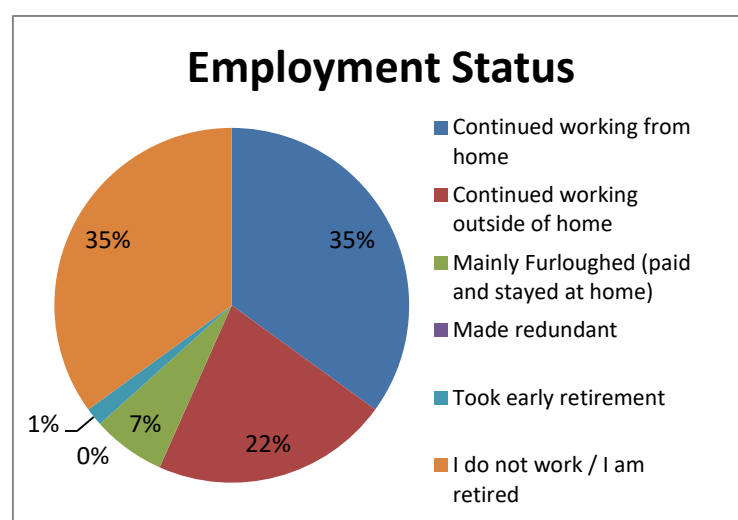


Figure 2.

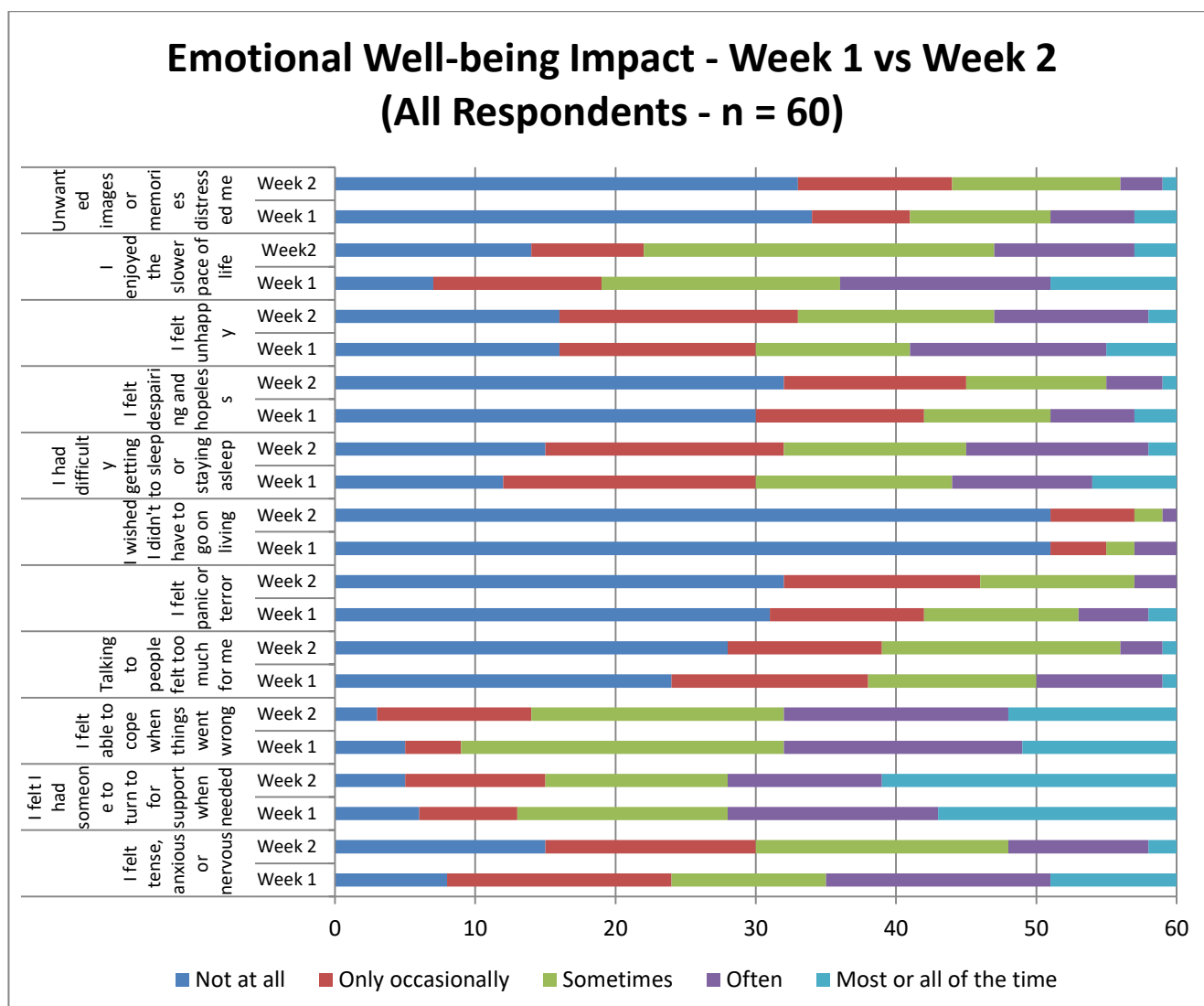


Results of the modified CORE-10 questionnaire from Week 1 were compared with those from Week 2. Overall, there is little significant difference in the impact on emotional well-being between the 1st national lock-down in Spring 2020 and October 2020^{Table 1/Figure 3}. However; of note is a slight reduction in the percentage of respondents feeling 'tense, anxious or nervous' either 'Often' or 'Most or All of the Time' by Week 2 compared to Week 1 (41.67% down to 20.00% respectively), and a corresponding increase in those feeling no anxiety, tension or nervousness at all (25.00% up from 13.33%). In addition, fewer people reported enjoying the slower pace of life either 'Often' or 'Most of the Time' in Week 2 compared to Week 1 (21.67% down from 40.00%), with almost double the number of respondents reporting to not enjoy it at all by Week 2 compared to Week 1 (23.33% up from 11.67%). This may in part be attributable to the 7% of respondents who were furloughed returning to work and having less 'down-time'.

Table 1: Results comparison of Week 1 vs Week 2 (all respondents)

N = 60	Not at all		Occasionally/ Sometimes		Often/ Most of the time	
	Week 1	Week 2	Week 1	Week 2	Week 1	Week 2
I felt tense, anxious or nervous	13.33%	25.00%	45.00%	55.00%	41.67%	20.00%
I felt I had someone to turn to for support when needed	10.00%	8.33%	36.67%	38.34%	53.33%	53.33%
I felt able to cope when things went wrong	8.33%	5.00%	45.00%	48.33%	46.66%	46.67%
Talking to people felt too much for me	40.00%	46.67%	43.33%	46.66%	16.67%	6.67%
I felt panic or terror	51.67%	53.33%	36.66%	41.66%	11.66%	5.00%
I wished I didn't have to go on living	85.00%	85.00%	10.00%	13.33%	5.00%	1.67%
I had difficulty getting to sleep or staying asleep	20.00%	25.00%	53.33%	50.00%	26.67%	25.00%
I felt despairing and hopeless	50.00%	53.33%	35.00%	38.34%	15.00%	8.34%
I felt unhappy	26.67%	26.67%	41.66%	51.66%	31.66%	21.66%
I enjoyed the slower pace of life	11.67%	23.33%	48.33%	55.00%	40.00%	21.67%
Unwanted images or memories distressed me	56.67%	55.00%	28.34%	38.33%	15.00%	6.67%

Figure 3.



We further analysed our data to compare the results of those with children (of any age) at home with those without^{Table2}, since women with children have been shown to fair worse in the UK¹.

Table 2: Results comparison of respondents with and without children at home

	Children at home?	Not at all		Occasionally/ Sometimes		Often/ Most of the time	
		Week 1	Week 2	Week 1	Week 2	Week 1	Week 2
I felt tense, anxious or nervous	Yes	0.00%	18.18%	72.72%	68.18%	27.28%	13.64%
	No	21.05%	28.95%	28.94%	47.37%	50.00%	23.68%
I felt I had someone to turn to for support when needed	Yes	4.55%	4.55%	40.91%	40.91%	54.55%	54.55%
	No	13.16%	10.53%	34.21%	36.85%	52.63%	52.63%
I felt able to cope when things went wrong	Yes	0.00%	4.55%	54.55%	50.00%	45.45%	45.46%
	No	13.16%	5.26%	39.47%	47.37%	47.39%	47.36%
Talking to people felt too much for me	Yes	36.36%	45.45%	54.54%	45.45%	9.10%	9.09%
	No	42.11%	47.37%	36.84%	47.37%	21.05%	5.26%
I felt panic or terror	Yes	45.45%	50.00%	45.46%	40.91%	9.09%	9.09%
	No	55.26%	55.26%	31.58%	42.10%	13.15%	2.63%
I wished I didn't have to go on living	Yes	86.36%	81.82%	9.10%	13.64%	4.55%	4.55%
	No	84.21%	86.84%	10.52%	13.16%	5.26%	0.00%
I had difficulty getting to sleep or staying asleep	Yes	18.18%	22.73%	59.09%	45.45%	22.73%	31.82%
	No	21.05%	26.32%	50.00%	52.63%	28.94%	21.05%
I felt despairing and hopeless	Yes	45.45%	59.09%	40.91%	27.28%	13.64%	13.64%
	No	52.63%	50.00%	32.02%	44.74%	15.79%	5.26%
I felt unhappy	Yes	27.27%	18.18%	40.91%	54.54%	31.82%	27.28%
	No	26.32%	31.58%	42.11%	50.00%	31.57%	18.42%
I enjoyed the slower pace of life	Yes	13.64%	36.36%	31.82%	31.82%	54.54%	31.82%
	No	10.53%	15.79%	57.89%	68.42%	31.58%	15.79%
Unwanted images or memories distressed me	Yes	68.18%	59.09%	22.73%	36.36%	9.10%	4.55%
	No	50.00%	52.63%	31.58%	39.47%	18.42%	7.89%

Our results did not show a significant difference in feelings between Week 1 and Week 2, with the exception of the following slight points of note once, including:

1. Those with children at home were more likely to feel occasionally or sometimes tense, anxious or nervous during both Week 1 and Week 2, while those without children at home felt this more often during Week 1.
2. Those without children at home were less likely to have someone to turn to for support than those with children, although the majority of our cohort felt that they did have someone to turn to either occasionally or most of the time in both Weeks.
3. In both Week 1 and Week 2, the vast majority of those with and without children at home did not report any feelings of not wanting to go on living (Week 1 86.36%/84.21%, Week 2 81.82%/86.84%), although it must be noted that around 13% of respondents did feel this occasionally/sometimes in Week 2.
4. Sleep was a varied picture, but around half of our respondents reported occasional difficulties in getting to sleep or staying asleep in both Week 1 and 2.
5. We see a reasonable difference in feelings of despair and hopelessness in people without children at home in Week 2 compared to those with children (44.74% vs 27.28%).
6. People without children at home were more likely to enjoy the slower pace of life in both Week 1 and Week 2, whereas those with children at home were more likely to enjoy this in Week 1 rather than Week 2.

Although Pierce et al (2020)¹ found no cause for concern, other studies have suggested that those with pre-existing conditions are more susceptible to anxiety and depression as a result of COVID-19². We therefore analysed our results further according to reported health status^{Table3}. Since no one reported their health status as ‘excellent’, we divided these results into Good or Very Good and Fair or Poor.

Table 3: Results comparison by health status (%) [Good/V. Good n = 34, Fair/Poor n = 26]

	Health Status	Not at all		Occasionally/ Sometimes		Often/ Most of the time	
		Week 1	Week 2	Week 1	Week 2	Week 1	Week 2
I felt tense, anxious or nervous	Good/V. Good	14.7%	32.4%	50.0%	50.0%	35.3%	17.6%
	Fair/Poor	11.5%	15.4%	38.5%	61.5%	50%	23.1%
I felt I had someone to turn to for support when needed	Good/V. Good	14.7%	11.8%	32.4%	35.3%	52.9%	52.9%
	Fair/Poor	3.9%	4.0%	42.3%	42.0%	53.8%	54.0%
I felt able to cope when things went wrong	Good/V. Good	8.8%	5.9%	35.3%	35.3%	55.9%	58.8%
	Fair/Poor	7.7%	3.8%	57.7%	65.4%	34.6%	30.8%
Talking to people felt too much for me	Good/V. Good	50%	58.8%	38.2%	38.2%	11.8%	3.0%
	Fair/Poor	26.9%	30.8%	50.0%	57.7%	23.1%	11.5%
I felt panic or terror	Good/V. Good	58.8%	55.9%	32.4%	38.2%	8.8%	5.9%
	Fair/Poor	42.3%	50.0%	42.3%	46.2%	15.4%	3.8%
I wished I didn't have to go on living	Good/V. Good	88.2%	94.0%	11.8%	6.0%	0.0%	0.0%
	Fair/Poor	80.8%	73.1%	7.7%	23.1%	11.5%	3.8%
I had difficulty getting to sleep or staying asleep	Good/V. Good	29.4%	32.4%	44.1%	38.23%	26.5%	29.4%
	Fair/Poor	7.7%	15.4%	65.4%	65.4%	26.9%	19.2%
I felt despairing and hopeless	Good/V. Good	61.8%	64.7%	23.5%	32.3%	14.7%	3.0%
	Fair/Poor	34.6%	38.5%	50%	46.1%	15.4%	15.4%
I felt unhappy	Good/V. Good	29.4%	38.2%	44.1%	44.1%	26.5%	17.7%
	Fair/Poor	23.0%	11.5%	38.5%	61.5%	38.5%	27.0%
I enjoyed the slower pace of life	Good/V. Good	14.7%	23.5%	50%	58.9%	35.3%	17.6%
	Fair/Poor	7.6%	23.1%	46.2%	50.0%	46.2%	26.9%
Unwanted images or memories distressed me	Good/V. Good	52.9%	55.9%	29.4%	38.2%	17.7%	5.9%
	Fair/Poor	61.5%	53.8%	27.0%	38.5%	11.5%	7.7%

Differences in responses were a little more marked in this analysis, although not significantly so. Of note are the following:

1. Those who described their health as ‘Fair’ or ‘Poor’ were slightly more likely to feel tense, anxious or nervous most of the time in both Week 1 and Week 2.
2. Those with poorer health were much more likely to feel that talking to people was too much for them in both Weeks.
3. Those with poorer health were the most likely to express feelings of wishing they didn't have to go on living than those with better health, particularly in Week 2 (23.1% vs 6.0% occasionally). Although this represents just 6 out of our 60 total respondents, this is a significant finding for a patient support group and one that requires further attention.
4. Those with poorer health were more likely to report occasional difficulties with sleep than those with better health in both Week 1 and Week 2.
5. People with better health were half as likely to feel occasional despair and hopelessness in both Week 1 and Week 2.
6. Although both groups more frequently felt occasional unhappiness in both weeks, this doubled in Week 2 for those with poorer health.

Discussion:

Although we cannot ascertain from our data whether or not there has been a decline in emotional well-being during the pandemic compared with previous years, it gives us an important snapshot of how our rare disease community is coping currently. Our original intention was to compare the results of the different types of diseases for which AMEND provides support; however, due to the low numbers of responses from those with ACC or inherited paraganglioma syndromes, we could only look at MEN syndromes as a whole. It may have been interesting to examine the differences between types of MEN syndrome, but this has not been possible.

The pandemic appears to have had a slightly more negative affect on the mental health of those with poorer health status, in line with the study by Iob et al (2020)²; however, we didn't see any significant difference in impact on those either with or without children, nor on the community as a whole. We did not ask whether our respondents had been subject to 'shielding' in the 1st national lock-down. This would most likely have applied to those with poorer health status, and may have shown an impact on results. Some results, as well as comments left by the respondents in the free text box, have given us an additional useful picture of the pandemic challenges for as well as the information and support needs of our community.

'My partner felt too anxious to return to work as a teaching assistant after the lockdown, for fear of catching the virus and passing it on to me..'

'I'm a driving instructor so it was difficult to know when it'd be safe to return. I went back a month after others because of being vulnerable'

'It did me a favour; gave me a reason to stay off work as my health has been so poor.'

'Was never sure if I should be going to work or shielding, GP not able or unwilling to answer specific questions, had difficulty with GP when I tried to refill my hydrocortisone emergency injection kit.'

'Health services I was awaiting were cancelled and tests on calcium levels didn't happen'

'Would have liked more info on how this would affect me compared to the norm'

Overall, these data provide us, as a patient organisation, a view of the needs of our community; namely the need for regularly updated information on the effect of coronavirus on our diseases, as well as the need to reinforce the availability of our free Counselling Service for those who are coping less well. This is in part in line with the call for more resources for and research investment in to those experiencing mental health problems during the pandemic³. In order to track any changes in these results going forwards, we will distribute a refined version of the survey once the pandemic is over.

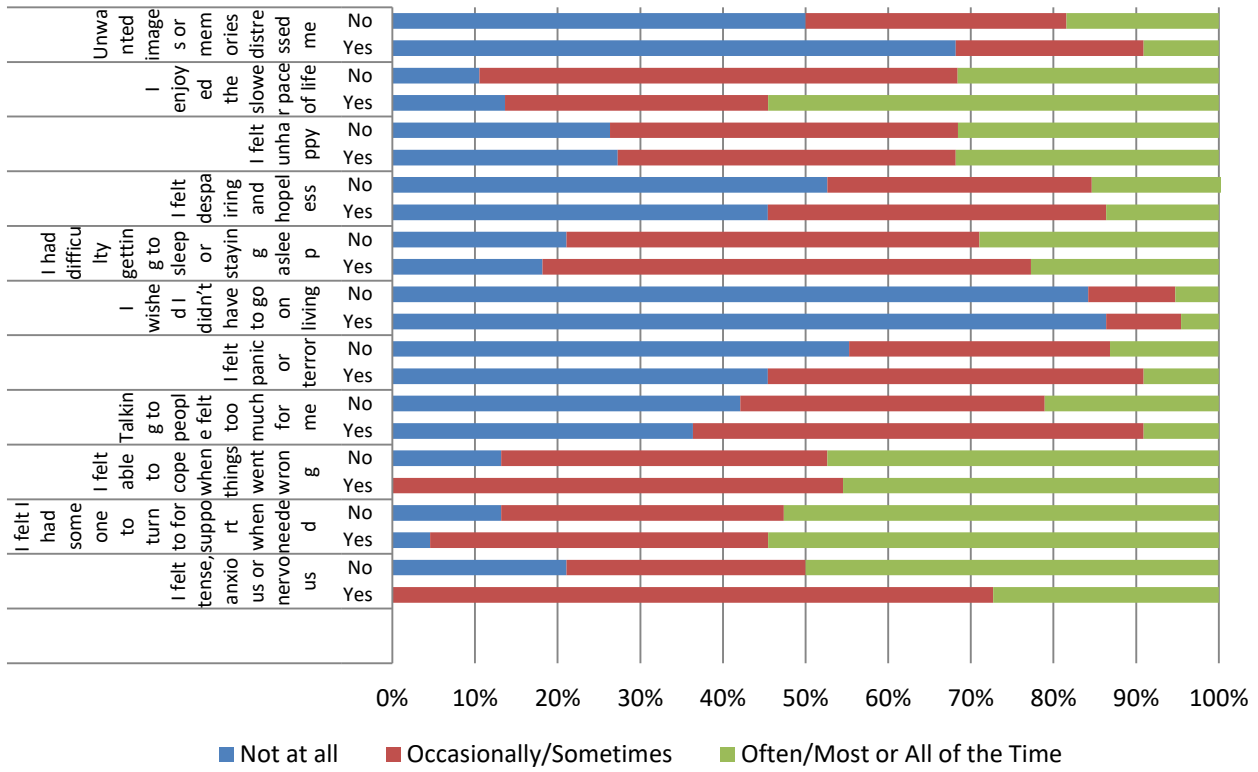
'Personally I coped with lockdown by protecting myself and others by following the guidelines, taking advantage of online shopping and home deliveries that had been put in place in my community. Most of all, keeping my mind and body active and maintaining a routine as far as possible.'

References:

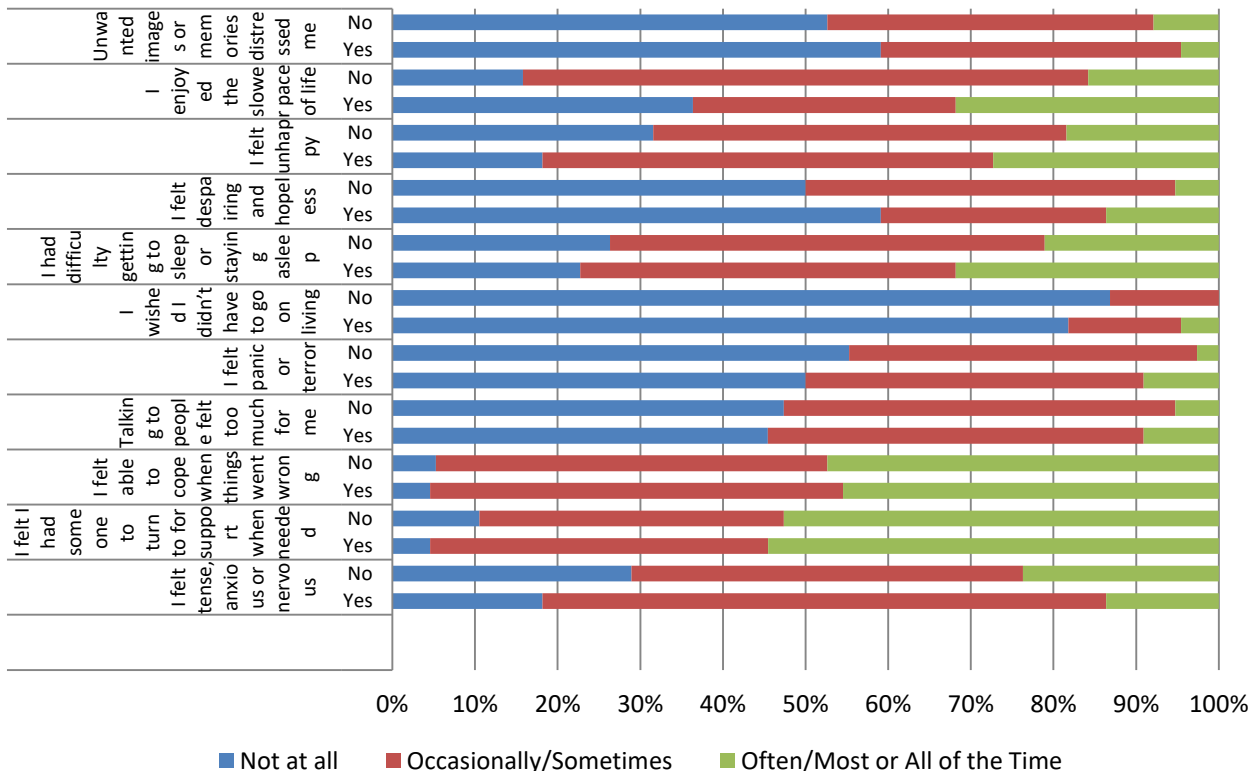
1. Pierce, M. et al, Mental Health before and during the COVID-19 pandemic: a longitudinal probability sample survey of the UK population. *Lancet Psychiatry* 2020; 7: 883-92. July 21, 2020. (accessed 09/11/2020)
2. Iob, E. et al, Levels of Severity of Depressive Symptoms Among At-Risk Groups in the UK During the COVID-19 Pandemic, *JAMA Network Open*. 2020;3(10):e2026064. (accessed 10/11/2020)
3. Holmes EA, O'Connor RC, Perry VH, et al. Multidisciplinary research priorities for the COVID-19 pandemic: a call for action for mental health science. *Lancet Psychiatry*. 2020;7(6):547-560.

Charts:

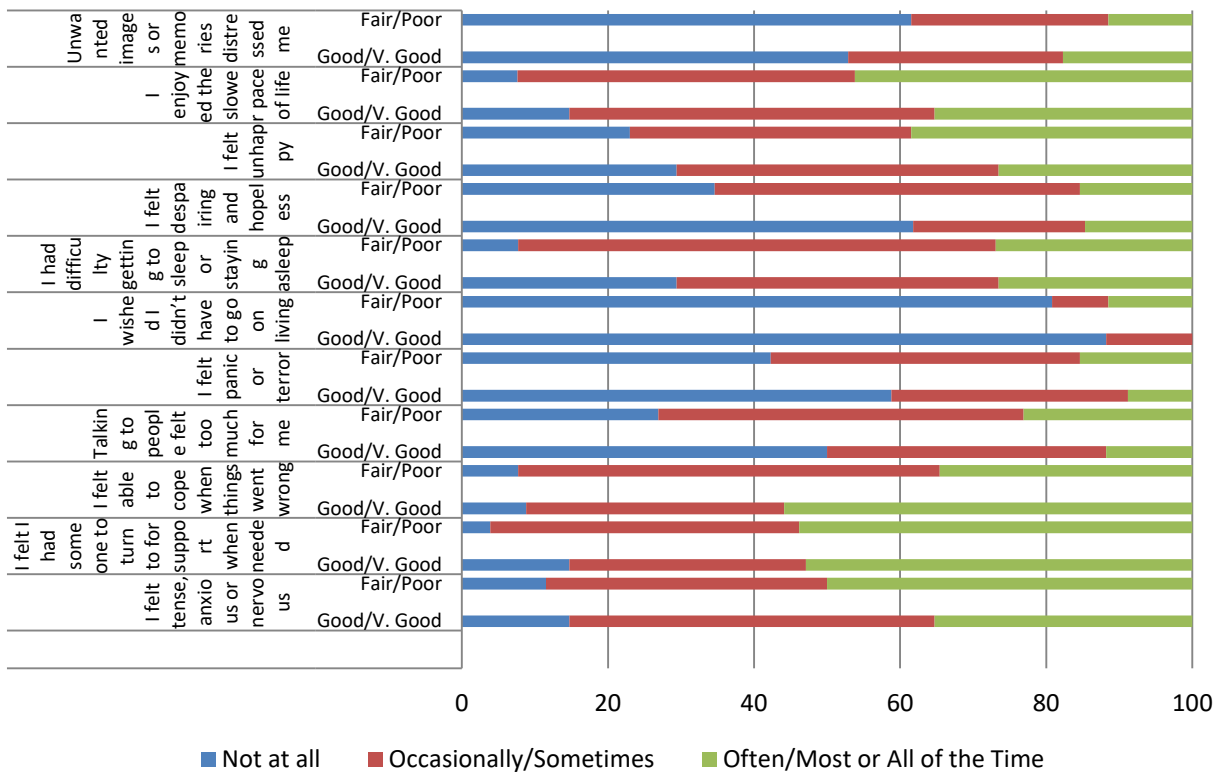
Impact of Children at Home - Week 1 (%)



Impact of Children at Home - Week 2 (%)



Emotional Impact by Health Status - Week 1 (%)



Emotional Impact by Health Status - Week 2 (%)

