

# Health Perception and Behavior Changes in Survivors of the Acute Respiratory Distress Syndrome

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### ABSTRACT

The Acute Respiratory Distress Syndrome (ARDS) is a severe illness with a 40% mortality rate. Improvements in care have reduced deaths but led to an increasing number of survivors who experience chronic adverse effects. However, there are no published studies that have evaluated changes in health perceptions and behavior in ARDS survivors. We sought to determine changes in health-related perceptions and behaviors in ARDS survivors. A sequential mixed methods study was conducted to examine changes in health perceptions and behaviors in ARDS survivors. Respondents were registrants at the ARDS Foundation, a non-profit patient support and education organization. Findings from interviews conducted with ARDS survivors during the initial qualitative phase were used to construct a quantitative survey instrument, which was completed by 229/513 (45%) registrants. Changes were reported in the following behaviors before and after ARDS: diet (34% and 31% consumed more fruits and vegetables, respectively, now than before ARDS, while 4% and 6%, respectively, said they consume less), physical activity (64% exercise now vs. 50% before,  $p < 0.01$ ), alcohol use ( $2.3 \pm 7.6$  drinks/week now vs.  $4.2 \pm 10.6$  before,  $p < 0.001$ ), and medical care needs ( $10.6 \pm 15.5$  doctor visits now vs.  $3.7 \pm 6.8$  before,  $p < 0.001$ ). ARDS survivors reported mostly positive health perception and behavior changes after their illness.

### PROBLEM

ARDS survivors' subsequent health perceptions and behaviors change after their illness is unknown.

### PURPOSE

In this study, we attempt to gain understanding of the health-related perceptions and behaviors of survivors of ARDS, and how these change after their illness.

**Table 1. Identified themes of health behavior in ARDS survivors.**

Changed dietary habits
Increased physical activity
Increased medication use and healthcare provider visits
Less health-averse recreational activities
Increased concerns about ARDS recurrence
Current medical care needs

### RELEVANT LITERATURE

Desai, S.V., Law, T.J., & Needham, D.M. (2011). Long-term complications of critical care. *Critical Care Medicine*, 39(2), 371-379.

Hopkins, R.O., Gale, S.D., & Weaver, L.K. (2006). Brain atrophy and cognitive impairment in survivors of Acute Respiratory Distress Syndrome. *Brain Injury*, 20(3), 263-271.

Herridge et al. (2003). One-year outcomes in survivors of the acute respiratory distress syndrome. *New England Journal of Medicine*, 348(8), 683-693.

### RESEARCH QUESTIONS

Do health perceptions and behavior change in survivors of ARDS compared to before their illness?

If so, what perceptions and behaviors change and to what extent?

### PROCEDURES

This was a mixed-methods study consisting of an initial qualitative interview followed by a quantitative survey. In the qualitative phase, 10 potential interviewees were randomly selected from the ARDS Foundation registry (a USA-based non-profit patient support and education organization for ARDS survivors) and invited to participate in a brief phone interview. Relevant and common themes relating to health behaviors were identified in this first phase (Table 1) and used to develop the more detailed and focused survey questions for the quantitative phase of the study.

All adult registrants of the ARDS Foundation (N=513) were sent an email with the web link, inviting them to participate in the quantitative survey.

### DATA ANALYSIS

For the qualitative phase, the authors conducted a content analysis of the transcripts. These data were used to create the survey questions for the secondary quantitative phase of the study, the online survey. The survey data were downloaded and analyzed using the STATA 10.0 software program (StataCorp; College Station, TX). Descriptive analyses were performed for all variables. Statistical correlations were used for different demographic groups' responses or responses before and after ARDS. Associations between categorical variables were assessed using a Chi square test and p-values  $< 0.05$  were considered statistically significant for all comparisons.

### FINDINGS

Most of the changes reported in this study were towards more healthy behaviors, such as improved physical activity and dietary habits and decreased tobacco and alcohol use (Figure 1). Table 2 summarizes the survivors' demographic information and Table 3 demonstrates changes in health perceptions and behavior in ARDS survivors compared to before their illness.

**Table 2. Survivors' demographics**

Demographics	Result
Total respondents (% response rate)	229 (45%)
Age (yr)	46±12
Gender (% female)	76%
Ethnicity (% Caucasian)	93%
Highest level of education	
High School	41%
College	54%
Annual family income	
< \$50,000	39%
\$50,000 - \$100,000	26%
> \$100,000	21%
Prefer not answer	14%
Years since ARDS (median)	4

**Table 3. Changes in health perceptions and behavior compared to before ARDS**

Perception/Behavior	Less	Same	More
Importance of health	0%	6%	89%
Time spent on health	5%	18%	77%
Money spent on health	4%	23%	73%
Visits to Emergency Centers	11%	20%	30%
Take medications for anxiety or depression	12%	39%	49%
Take vitamins $\geq$ once a week	3%	24%	43%

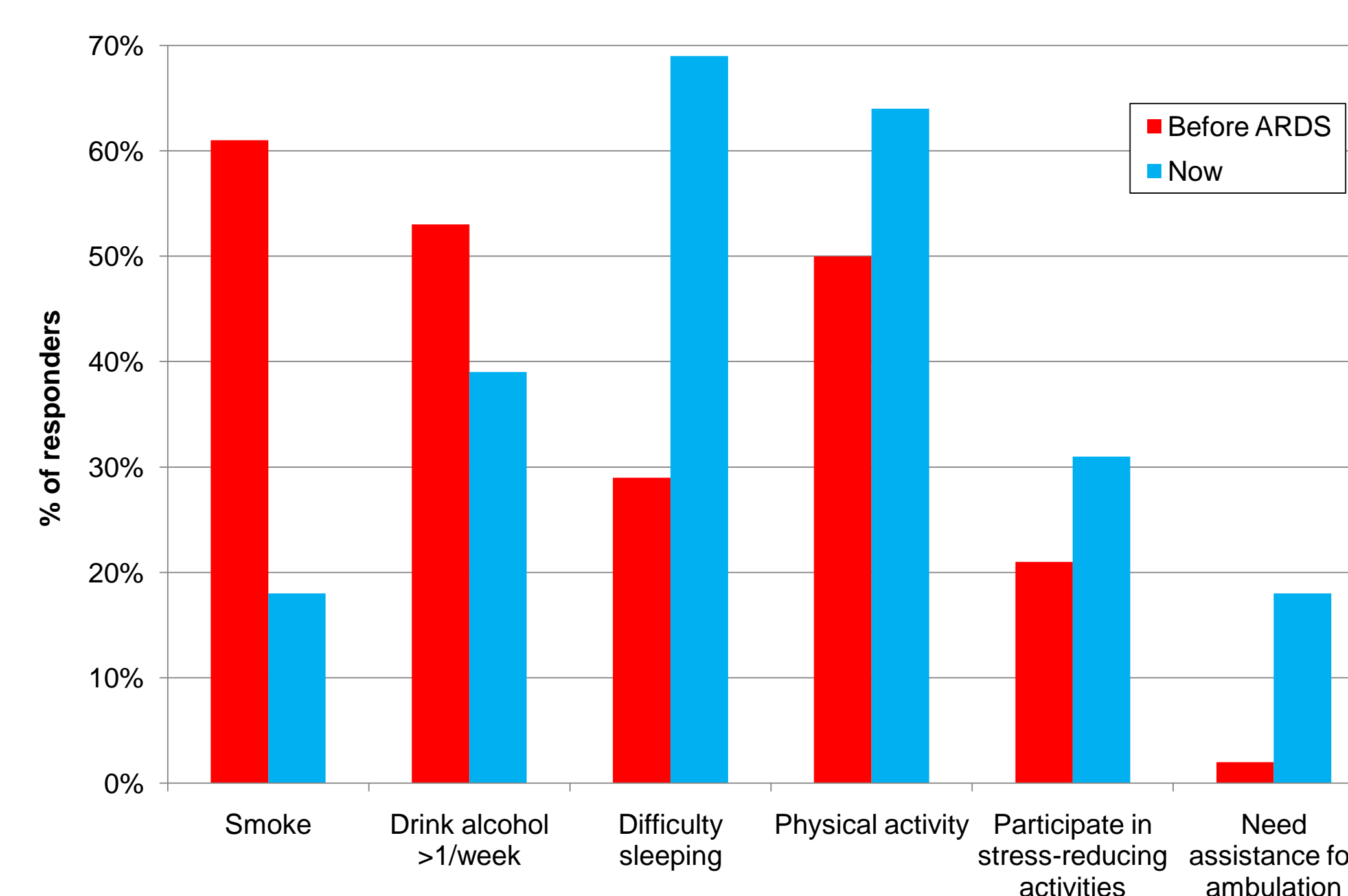
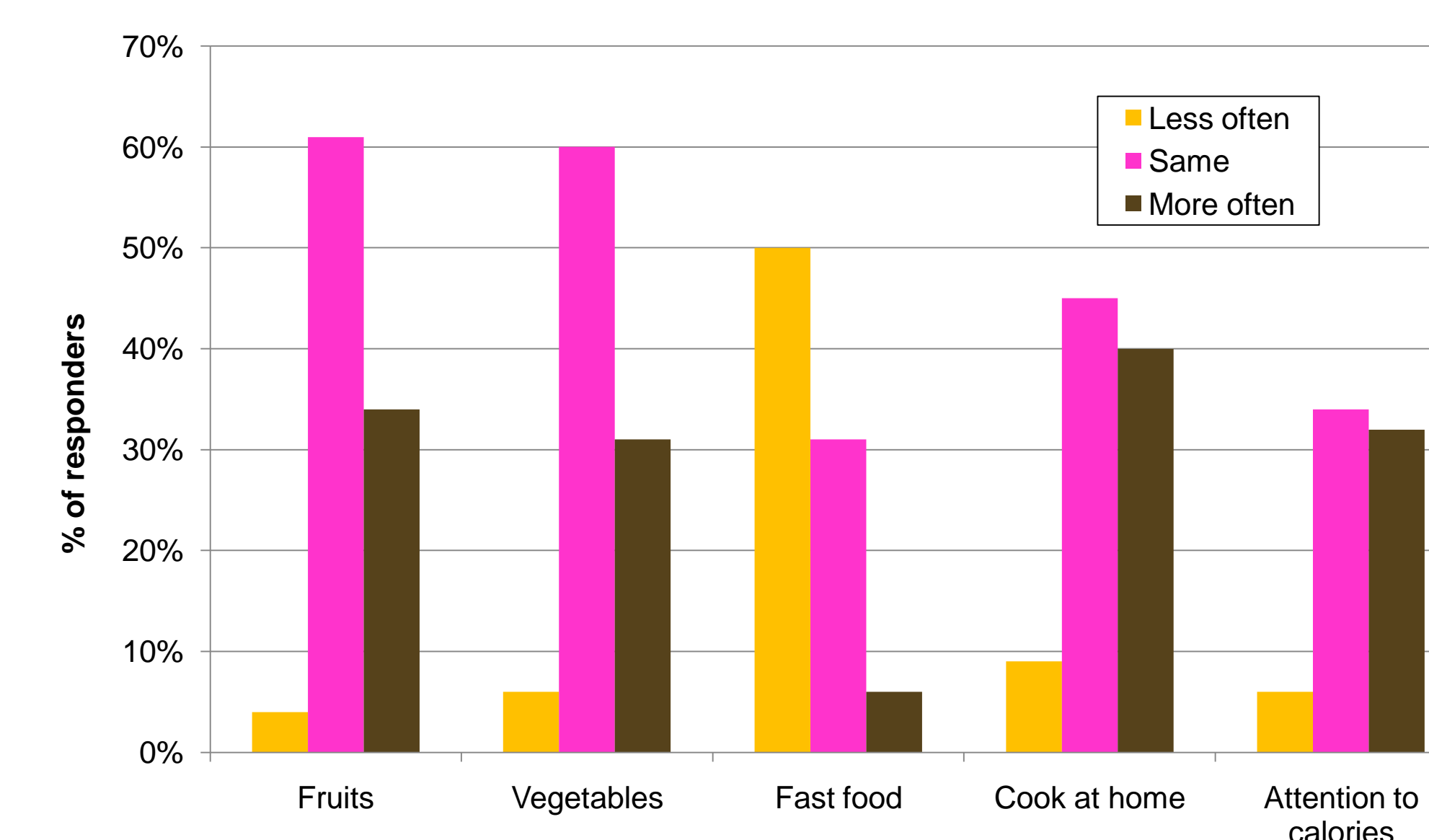


Figure 2 demonstrates changes in eating habits after ARDS.



### LIMITATIONS

Our source of data was a patient-support organization whose registrants may be more educated and have more access to web-based materials and information.

- Our study relied on recall information from survivors, many of whom experienced ARDS years prior or may suffer from neuro-cognitive deficits.
- Items measured may contribute to social desirability responsiveness.
- Objective data on disease severity was not collected.
- We did not measure quality of life after ARDS, an important determinant and consequence of health behavior and perceptions.

### CONCLUSIONS

Our results demonstrated that respondents did make significant changes in their health behavior and perceptions after ARDS across several domains and among all demographic groups. These changes were mostly towards healthier behaviors, such as better diets and more exercise. These changes may indicate that survivors of a critical illness such as ARDS develop better health behaviors and are more vigilant about their new state of health. Further research is needed to determine if these changes have significant implications on patients' long-term health outcomes.

### SOCIAL CHANGE IMPLICATIONS

The data indicate that health behavior changes do indeed occur for some survivors of a severe illness. The post critical illness period therefore may represent an opportunity to promote, facilitate, and guide healthier behaviors.