



BACKGROUND

Head & Neck Cancer (HNC) survivors experience significant long-term side effects of their treatment, and health-related quality-of-life (HRQoL) assessments of HNC survivors are still early in development. This survey captured long-term nutrition impact symptoms, eating problems, psychosocial impact, and barriers to accessing health care of HNC survivors.

AIMS

This survey is among the first systematic attempts to try to capture long-term nutrition impact symptoms & the psychosocial impact of these eating problems on HNC survivors. It aimed to:

- (1) Collect information on the prevalence and persistence of long-term eating problems experienced by HNC survivors
- (2) Capture psychosocial impact of these eating problems and what care HNC survivors access to address these impacts
- (3) Identify barriers to HNC survivors in receiving cancer treatment and supportive care for eating problems
- (4) Inform Cancer Support Community's (CSC's) *Frankly Speaking About Cancer: Head & Neck Cancer* program materials

METHODS

- The Cancer Support Community (CSC) conducted an online survey between March and May 2020.
- CSC, Head and Neck Cancer Alliance, and Support for People with Oral and Head and Neck Cancer (SPOHNC) recruited potential survey respondents.
- 214 people who had been diagnosed with HNC responded.
- 172 of those respondents were "long-term survivors" (LTS), at least 2 years past initial diagnosis.
- To focus on long-term impact, only LTS were asked the full set of survey questions. Respondents less than 2 years past initial diagnosis were only asked their type of cancer and barriers to accessing treatment.

RESULTS FOR ALL RESPONDENTS

Type of Head & Neck Cancer (n=214)

- 58% Oral cavity or lip cancer
- 29% Pharynx (throat)
- 10% Larynx (voice box)
- 8% Salivary gland
- 5% Nasopharynx
- 17% Oropharynx
- 13% Hypopharynx
- 5% Nasal cavity
- 6% Other

Barriers to Receiving Cancer Treatment (n=185-198)

- Cost of Treatment (19%)
- Cost of Other Medications (18%)
- Distance to treatment (18%)
- Family's inability to take time off from work (14%)
- Respondent's inability to take time off from work (11%)
- Cost of Transportation (10%)
- Access to Transportation (9.1%)
- Access to Child Care (1%)
- Cost of Child Care (0.5%)

RESULTS FOR LONG TERM SURVIVORS (LTS, ≥2 years past initial diagnosis, n=172)

	Mean/n	SD/%
Age (years) (range 35-86)	63.7	9.9
Race & Ethnicity		
White	162	94%
Black	8	5%
Hispanic	4	2%
Asian	1	<1%
Gender Identity		
Woman	101	58%
Man	71	41%
Transgender female/Trans woman	1	<1%
Highest Degree/Level of School Completed		
Some high school	1	<1%
High school, trade school, or GED	25	15%
Some college	36	21%
Associate degree	19	11%
Bachelor's degree	58	34%
Graduate degree or higher	31	18%
Year First Diagnosed with HNC		
1995 or earlier	6	4%
1996-2000	14	9%
2001-2005	18	11%
2006-2010	28	17%
2011-2015	37	23%
2016-2018	60	37%

Note: Data for "Prefer not to share" responses omitted.

LTS STAGE AT INITIAL DIAGNOSIS

- 1% Stage 0
- 10% Stage I
- 16% Stage II
- 32% Stage III
- 28% Stage IV (Metastatic)
- 11% I don't know
- 2% Other

25% of LTS reported the cancer ever recurring

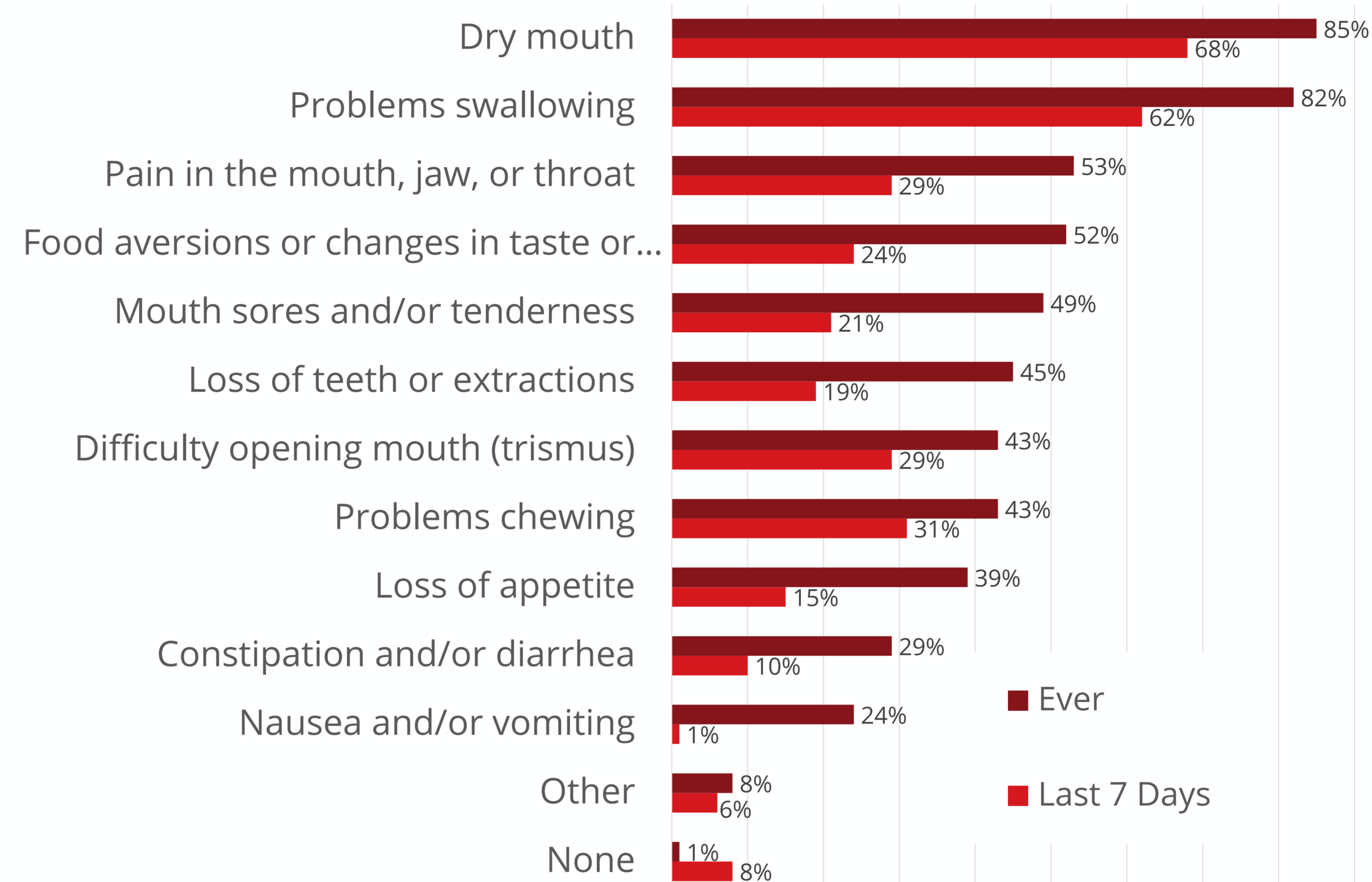
LTS CANCER TREATMENT RECEIVED

- 93% Radiation Therapy
- 66% Surgery
- 59% Chemotherapy
- 11% Targeted Therapy
- 8% Immunotherapy
- 6% Clinical Trials
- 1% Other Treatment

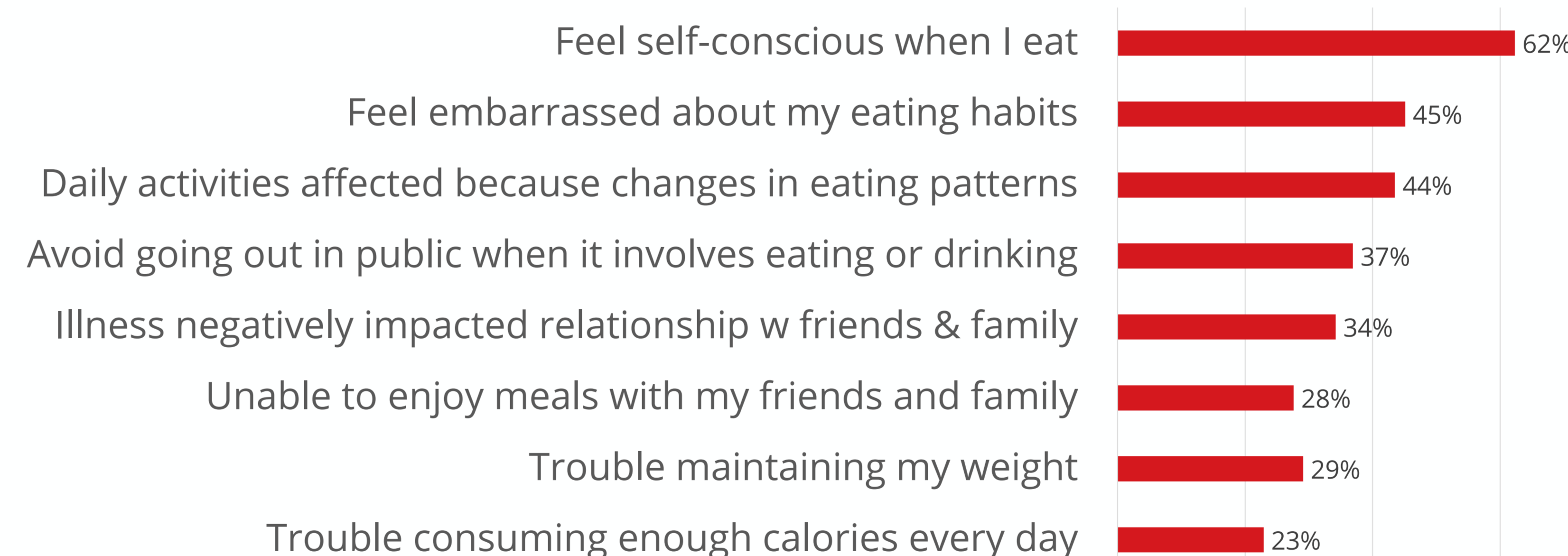
LTS DIET/FEEDING TUBE USE

- 42.2% of LTS reported currently being unable to eat solid foods
 - 29.5 reported eating a "soft" food diet
 - 9% reported their diet was primarily by feeding tube
 - 3.6% reported a liquid by mouth or pureed diet
- 29.1% of respondents reported having trouble maintaining
- 63% LTS ever used a feeding tube (FT)
- Weaning from a FT was mostly likely before 14 months
 - For LTS weaned, 71% used FT for ≤6 months
 - Current FT users had them for a median of 39 months

LTS SIDE EFFECTS – EVER & LAST 7 DAYS



NEGATIVE IMPACTS TO LTS SOCIAL LIFE



CONCLUSIONS AND IMPLICATIONS

- Although HNCs are generally considered "curable," the nature of the disease and the required aggressive treatment regimens leave LTS with a broad range of common physical and psychosocial issues that are rarely addressed. In addition to the barriers to receiving cancer treatment reported by all respondents, LTS had difficulty paying for and accessing care to manage eating problems and their impacts.
- Survey data highlight almost universal, long-term persistence of eating and nutrition problems which cause significant psychosocial impact over LTS' lifetime. Most common physical issues were dry mouth and problems swallowing and chewing, resulting in 42% of LTS unable to eat a solid food diet. Most common impacts were needing supplemental nutrition drinks, ever needing a feeding tube, feeling self-conscious or embarrassed when eating, changing daily activities, and avoiding eating in public.
- More research on long-term side effects in LTS of HNC is needed, as is systems change to provide access to care for managing these side effects.

For LTS in the last 7 days:

- 92% reported eating problems
- 68% had dry mouth
- 62% had swallowing problems

For LTS ever:

- 99% experienced eating problems
- 85% experienced dry mouth
- 82% experienced swallowing problems

Side effects were reported by LTS at every stage of cancer and all ranges of time since diagnosis

LTS MANAGED PROBLEMS USING

- 64% - Supplemental nutrition drinks (like Ensure or Boost)
- 45% - Tube feeding formulas & supplies
- 37% - Products to help with side effects
- 35% - Consultations with a dietitian/nutritionist
- 32% - Dental Work
- 11% - Sessions with a counselor or therapist
- 6% - Other
- 13% - Did not need any of these

LTS had problems accessing care to manage eating problems & negative impacts:

- 27% never saw a health care professional (HCP) or mental HCP to manage problems & impact
- Only 11% of LTS ever met with mental HCP
- Male LTS of older age & those without Medicare were less likely to access HCPs (except dentists for Medicare recipients) and mental HCPs

LTS reported difficulty paying for:

- 29% - Dental work
- 11% - Supplemental nutrition drinks
- 9% - Products to help with side effects