






## ORIGINAL ARTICLE

# A prospective study monitoring carer distress during (chemo)radiotherapy for head and neck cancer via an electronic platform

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## Keywords

(Chemo)radiotherapy, distress, dysphagia, head and neck cancer, patient-reported outcomes, speech pathology

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## Abstract

**Introduction:** Research has shown that electronic platforms can assist data capture of patient-reported outcome measures (PROMs) to guide clinical care. In comparison, routine collection of carer-reported outcome measures (CROMs) to support the patient–carer dyad during cancer treatment has had limited attention. The current study utilised a novel electronic CROM (eCROM) system, *ScreenIT Carer*, to monitor the prevalence and nature of distress in carers of patients undergoing (chemo)radiotherapy ((C)RT) for head/neck cancer (HNC), and explore factors associated with carer distress. **Methods:** Carers completed *ScreenIT Carer* weekly when attending patients' (C) RT treatment sessions from planning to 2 weeks post-treatment. *ScreenIT Carer* included the Distress Thermometer (DT) and Problem List, and a purpose-built Mealtime-Specific DT and Problem list. Data were first examined descriptively, then associations between demographic/treatment-related factors and distress severity were analysed using mixed-effects general linear modelling. **Results:** 135 carers provided 434 *ScreenIT Carer* entries during the study period (mean entries = three/carers; yielding average adherence rate of 41% (range 11–100%)). A high prevalence of general (59%) and mealtime-specific distress (46%) was reported by carers. Nature of distress was multifactorial, with emotional problems and the patients' physical condition/symptoms common contributing factors. Based on multivariate analysis, tumour site, geographical location of residence and time during (C)RT when *ScreenIT Carer* was completed were significant predictors of carer distress severity. **Conclusions:** Carer distress is prevalent and multifactorial during (C)RT. This study highlights the feasibility of utilising eCROM platforms such as *ScreenIT Carer*, to monitor carer wellbeing and guide supportive care services as part of a holistic care pathway.

## Introduction

Caring for people undergoing curative radiotherapy with or without chemotherapy ([C]RT) for head/neck cancer (HNC) has been shown to contribute to a high incidence

of carer psychological distress (16–77%).<sup>1–3</sup> Carers of patients with HNC have reported a greater severity and persistence of psychological distress following (C)RT than patients themselves, as well as the general population,<sup>1,4,5</sup> with increased hours of care,<sup>5</sup> reduced patient health-

related quality of life (QoL)<sup>1,4-6</sup> and lower perceived social support,<sup>7</sup> associated with poorer psychological health outcomes for carers.

The use of (C)RT, delivered on an outpatient basis, has increased the burden of care placed on carers to manage patients' physical side-effects at home,<sup>8</sup> often with limited formal guidance or support.<sup>9</sup> Dysphagia is one of the common sequelae of (C)RT, contributing to functional debility and poorer QOL in patients, and associated impacts to carer psychosocial outcomes.<sup>10</sup> Qualitative studies have revealed that, irrespective of dysphagia severity, caring for patients with HNC who have dysphagia is considered a major lifestyle adjustment for carers, with many experiencing increased burden with regards to mealtimes and restrictions to social participation.<sup>10-13</sup>

Despite the documented burden of (C)RT on carers during treatment,<sup>1-5</sup> the identification and management of carer distress has not been routinely accommodated in the clinical setting, due to time and resource constraints.<sup>14</sup> When faced with similar service challenges regarding detection and management of distress in patients with HNC, novel methods have been considered, including electronic screening platforms developed to capture patient-reported outcome measures (ePROMs). ePROM systems have been shown to improve consumer-provider communication<sup>15</sup> by allowing data capture, collation and synthesis for the multidisciplinary team (MDT) in real-time, assisting in the early detection of problematic symptoms, and psychosocial concerns,<sup>16,17</sup> and resulting in more timely and individualised care.<sup>18-21</sup>

Despite the reported advantages of ePROMs, there has been limited investigation into the use of electronic systems to deliver 'carer-reported outcome measures', (eCROMs). Co-collecting carer and patient-reported distress and concerns during HNC treatment could provide a means to map carer needs against current patient functioning, and inform the development of supportive care services and enable carers to be co-partners in HNC management. Further research is needed to explore the clinical applicability of eCROMs to monitor the psychosocial and practical impacts of (C)RT on the carers of patients with HNC, and the utility of using electronic measures to monitor these impacts across the treatment continuum. Therefore, the primary aim of the current study was to trial the use of a novel eCROM system, *ScreenIT Carer*, to monitor the prevalence and nature of general and mealtime-specific distress in carers of patients with HNC undergoing (C)RT. The secondary aim was to explore demographic and treatment factors associated with severity of carer distress.

## Methods

### Study design and setting

This was a prospective observational cohort study of carers and/or family of patients with HNC treated through the Metro South Radiation Oncology Service (MSROS), a quaternary hospital and cancer centre in Brisbane, Australia. The study involved repeated measures data collection of carer distress data using a bespoke eCROM tool.

### Participants

The study participants were carers of patients with HNC receiving (C)RT at MSROS between June 2015 and July 2019. The patient cohort was consecutively treated patients receiving curative-intent (C)RT for a primary diagnosis of HNC. Treatment duration ranged from 5 to 7 weeks depending on cancer type. Carers were excluded from participating if they had significant language, cognitive or access impairments that would limit access to the *ScreenIT Carer* platform, or if the patient did not consent to the use of *ScreenIT*.

Ethical approval was obtained (HREC13/QPAH/437), and written consent was gained from participants from 2015 to 2016. From 2016 onwards, *ScreenIT* was implemented into standard care at MSROS, and patients and carers provided consent for data collection and analysis through the platform as part of their standard consent for treatment.

### ScreenIT Carer system

*ScreenIT Carer* is a computerised screening system conceptualised by Wall et al.<sup>20</sup> to capture carer-reported information regarding general and mealtime-specific distress during (C)RT treatment. *ScreenIT Carer* was designed as part of a larger *ScreenIT* platform which provides a suite of HNC-specific ePROMs to monitor symptoms, functional and psychosocial status in patients with HNC.<sup>20</sup> *ScreenIT Carer* was accessed by carers via secure login either in the Radiation Oncology Department waiting area, or from home.

The content of *ScreenIT Carer* is organised into four domains including: basic demographic information (name and relationship to patient), general distress, mealtime-specific distress and need for supportive care services. The National Comprehensive Cancer Network (NCCN) Distress Thermometer (DT) was used to measure perceived level of general distress.<sup>22</sup> A DT score of >4 was indicative of a clinically significant level of distress

requiring intervention (DT < 4 no or mild distress; 4–7 moderate distress; 8–10 severe distress).<sup>23</sup> If any level of distress was reported (DT > 0), carers are asked to select contributing factors to their distress score from the DT Problem List.<sup>22</sup>

The DT was also used to rate mealtime-specific distress, with a modified version of the Problem List developed specifically for this research and derived from previous qualitative research exploring the nature of carer distress in HNC and dysphagia<sup>24</sup> (Appendix S1). Participants were also asked to indicate (yes/no) if they desired a referral to discuss their (a) general or (b) mealtime-specific concerns with a health professional. Overall, *ScreenIT Carer* took participants approximately 2 min to complete. After completion of *ScreenIT Carer*, a summary report was automatically generated for clinicians to review. Referral pathways to the MDT, based on risk management algorithms developed by Wall *et al.*<sup>20</sup> in consultation with MSROS, were then actioned based on the summary report information (see Appendix S2 for further details).

## Procedure

Eligible participants were recruited and oriented to the *ScreenIT* platform at radiotherapy planning. Consenting carers were encouraged to complete *ScreenIT Carer* once each week from planning until 2 weeks post (C)RT treatment, at the same time as patients. Reminders to complete *ScreenIT* were included as part of the patients' treatment schedules; however, no specific reminders were provided to carers. There were no rules set regarding mandatory attendance of carers during the treatment appointments, rather, the expectation was that carers would complete *ScreenIT Carer* when they were in attendance.

Carer demographic data including gender, relationship to patient and time during treatment when *ScreenIT Carer* was completed were gathered from the *ScreenIT* system. Patient demographics including age, gender, geographical location of residence, HNC site and stage, treatment type and treatment course were retrieved from medical records.

## Data analysis

Use of/adherence to the *ScreenIT Carer* system was analysed as a percentage, due to the variation in the length of treatment schedules (if patient's treatment schedule was 7 weeks, maximum number of *ScreenIT Carer* entries possible was 10 (including planning, and 2 weeks post-treatment)). Completion of  $\geq 80\%$  possible *ScreenIT Carer* entries was deemed 'fully adherent', whilst

33–79% completion was deemed 'partially adherent'. Descriptive statistics were used to analyse demographic data, DT ratings and Problem List items. Analysis of association between demographic factors and carer distress was conducted at the univariable level using ordinary least squares (OLS) regression, with the DT rating (0–10) used as the dependent variable. To facilitate analysis, categorical/ordinal predictor variables were collapsed into dichotomous form, including time when *ScreenIT Carer* was completed (early (pre-treatment to week 3) vs. late (week 4+)), HNC site (mucosal SCC vs. other), treatment type (radiotherapy only vs. multimodality) and carer relationship to patient (spouse/partner vs. other). Multivariable analysis was then conducted using general linear modelling (GLM) with Gaussian assumptions. Due to the size of the sample, only those variables which were significant ( $P < 0.05$ ) at the univariable level were included in the GLM. Model fit was checked using the Akaike Information Criterion. All statistical modelling was conducted using Stata version 13 software. Significance was set at  $P < 0.05$ . However, results  $\geq 0.05$ , but  $< 0.07$ , were also discussed as trends.

## Results

In total, 434 *ScreenIT Carer* entries were completed during the study period. Six entries were excluded as they were collected in response to patient re-treatment for a non-HNC, seven were excluded as they could not be matched to patient records, and five were excluded as they were completed more than 2 weeks post-treatment. This left 416 *ScreenIT* entries in the final analysis. These 416 entries were completed by 135 carers of 125 patients (eight patients each had two carers, one patient had three).

Most carers were female and a spouse/partner of patients who lived in metropolitan locations. Patients were predominately males in their late 60s, presenting with locally advanced mucosal SCCs treated with multimodality treatment (Table 1).

## Use of *ScreenIT Carer*

On average, participants completed *ScreenIT Carer* three times over the course of (C)RT (range = 1–10). The average adherence rate for the total cohort was 41% (range 11–100%). At the individual level, only 18% ( $n = 22$ ) of carers (or carer groups if there were multiple carers per patient) demonstrated full adherence (i.e.  $\geq 80\%$  completion of possible *ScreenIT Carer* entries). An additional 32% ( $n = 40$ ) were partially adherent (33–79% completion of possible entries), with 50% ( $n = 63$ ) classified as low adherers (<33% completion of possible

**Table 1.** Demographic information for eligible carers ( $n = 135$ ) and patients ( $n = 125$ ).

Demographics	% (n)
<b>Carer</b>	
Gender	
Male	22.96 (31)
Female	77.04 (104)
Relationship to patient	
Spouse/partner	62.22 (84)
Other (e.g. son/daughter, other family member)	37.78 (51)
<b>Patient</b>	
Gender	
Male	78.40 (98)
Female	21.60 (27)
Geographical location	
Metro	68.00 (85)
Regional/rural	32.00 (40)
Treatment type	
Radiotherapy	16.00 (20)
Post-operative radiotherapy	44.80 (56)
(Chemo)radiotherapy	39.20 (49)
Tumour site*	
Mucosal SCC	60.80 (76)
Other	39.20 (49)
T stage <sup>#</sup>	
T0–2	54.39 (62)
T3–4	45.61 (52)
N stage <sup>#</sup>	
N40.3	40.35 (46)
N1–3	59.65 (68)

\*Mucosal SCC = tumours of the nasal/nasopharynx, oral cavity, oropharynx, hypopharynx or larynx; other = skin, parotid/neck or other. #n=114.

entries). No carer attendance data were collected; therefore, the number of times carers did not complete *ScreenIT Carer* because they were not in attendance at treatment appointments could not be determined. For those carers who provided more than 1 *ScreenIT Carer* entry, 71% ( $n = 55/77$ ) provided data in both the early (planning-week 3) and later (week 4–10) phases of (C)RT.

### Prevalence and pattern of carer general distress

Of the total *ScreenIT Carer* entries, 45% (187/416) indicated a clinically significant level of general distress ( $DT \geq 4$ ). Of these ( $n = 187$ ), 86.1% ( $n = 161$ ) indicated a moderate level of distress (DT4-7) and 13.9% ( $n = 26$ ) indicated a severe level of distress (DT8-10). At the individual participant level, a total of 58% (79/135) of carers reported a clinically significant level of distress ( $DT \geq 4$ ) in one or more of their *ScreenIT Carer* entries

during/post-treatment. For these 79 carers, 75% ( $n = 50$ ) indicated a maximum level of moderate distress (DT4-7), whilst 25% ( $n = 20$ ) progressed to a severe level of distress (DT8-10) at one or more times during/post-treatment. Despite this high prevalence of general distress, carers requested a referral to discuss their distress with the MDT on only 4.3% ( $n = 18$ ) of entries.

The prevalence of general distress ( $DT \geq 4$ ) over time (by week) is shown in Figure 1. Overall, clinically significant carer distress peaked halfway through (C)RT at week 4. Severe carer distress was observed at a relatively consistent prevalence throughout treatment (approximately 4–10%), which peaked to 14.3% ( $n = 28$ ) at the end of treatment (week 7). Analysis of DT Problem List items contributing to carer general distress is shown in Figure 2. Emotional problems and concerns related to patients' physical problems were the most common contributors to carer distress, specifically including 'worry' (33.9%), 'fatigue' (29.6%) and 'eating/drinking problems' (26.9%) (Figure 2).

### Prevalence and pattern of carer mealtime-specific distress

In regards to mealtime-specific distress, 35.8% (149/416) of *ScreenIT Carer* entries indicated a clinically significant level of mealtime-specific distress, of which 13.4% ( $n = 20/149$ ) were severe. At the individual level, 46% (62/135) of carers reported a clinically significant level of mealtime-specific distress ( $DT \geq 4$ ) in one or more of their *ScreenIT Carer* entries. Of these, 73% ( $n = 45$ ) peaked at moderate distress (DT4-7), whilst 27% ( $n = 17$ ) experienced a severe level of mealtime-specific distress at one or more times during/post-treatment. Referrals to the MDT to discuss their mealtime concerns were requested on only 2.6% ( $n = 11$ ) of entries.

As seen in Figure 3, the prevalence of clinically significant mealtime-specific distress ( $DT \geq 4$ ) gradually increased throughout (C)RT. Similar to general distress, the highest prevalence of mealtime-specific distress was reported at week 4 (53.7%,  $n = 41$ ). Analysis of DT Problem List items revealed that 'eating/drinking' (26.4%), 'worry' (23.8%), 'fatigue' (22.4%) and 'knowing what food/drinks will be suitable' (20.4%) were the most common stressors amongst carers (Figure 4).

### Demographic and treatment factors associated with carer distress

#### General distress

Univariable analysis identified geographical location ( $P = 0.003$ ), treatment type ( $P = 0.038$ ) and tumour site

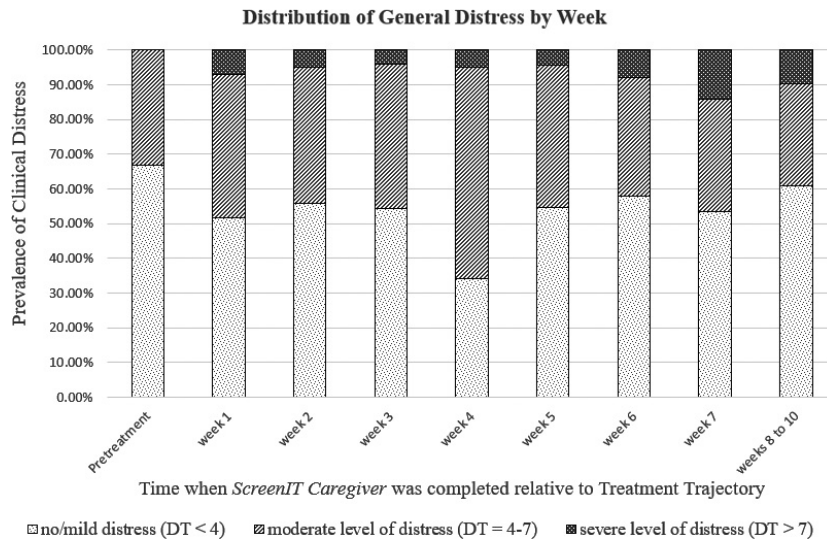


Figure 1. Distribution of general carer distress by treatment week.

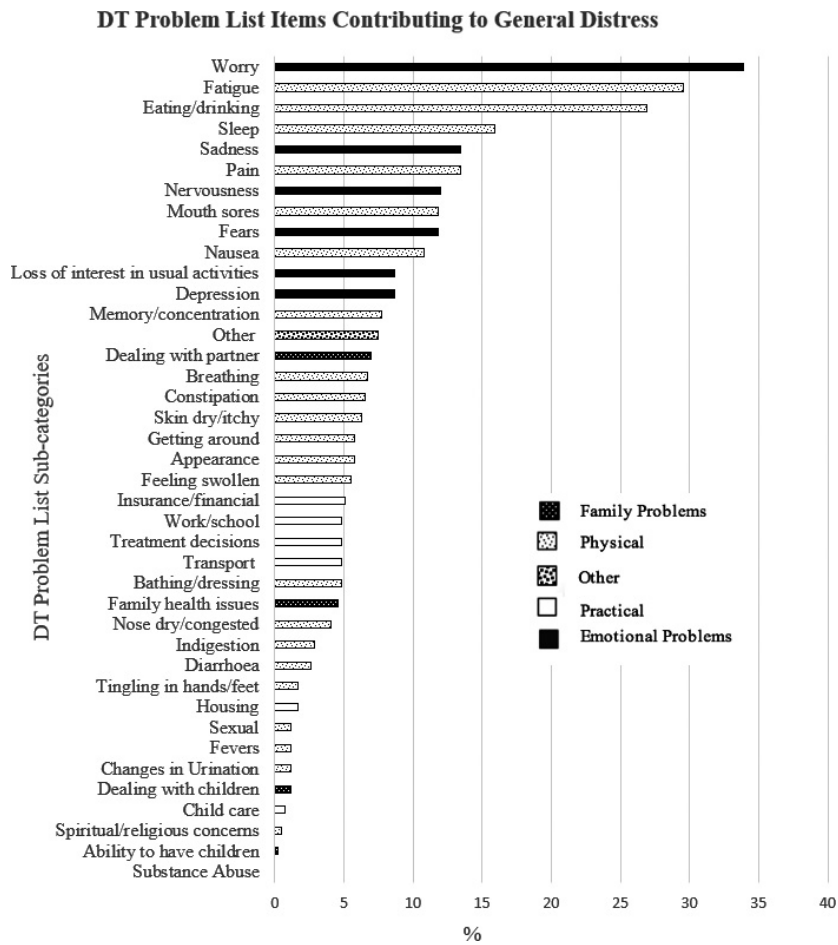


Figure 2. Contributing factors to general distress.

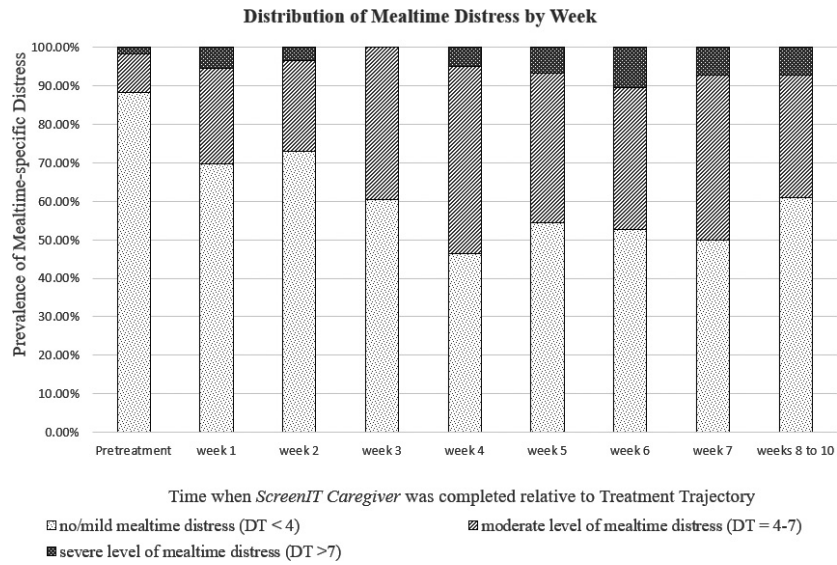


Figure 3. Distribution of mealtime-specific carer distress by treatment week.

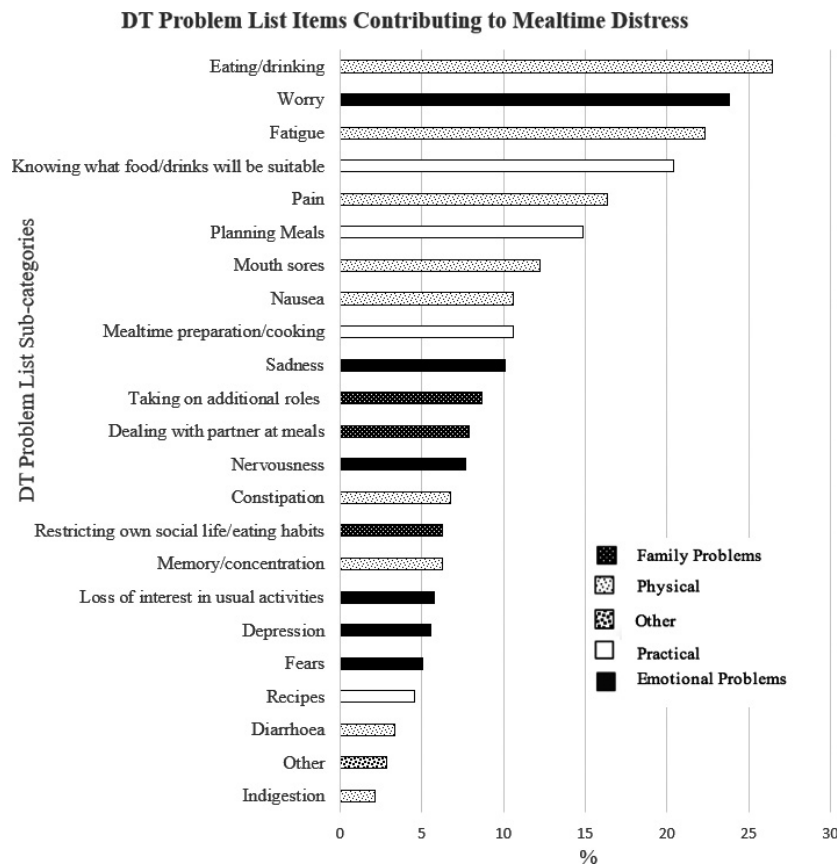


Figure 4. Contributing factors to mealtime-specific distress.

( $P = 0.012$ ) as significant factors associated with carer general distress (Table 2). Caring for a patient from a regional/rural location was a negative predictor of carer distress (i.e., associated with a lower severity of distress). Whereas, caring for a patient receiving multimodality treatment and caring for a patient with a mucosal SCC were both positive predictors of carer distress (i.e., associated with a higher severity of distress). Carer gender, relationship to patient and the time during treatment when *ScreenIT Carer* was completed were not found to be significant predictors of general distress at the univariable level.

In the final multivariable model, mucosal tumour site ( $P = 0.024$ ) remained a significant positive predictor of carer general distress (associated with a higher severity of distress). Geographical location trended towards significance at the multivariable level as a negative predictor of distress ( $P = 0.050$ ). Treatment type ( $P = 0.558$ ) was not a significant predictor of general distress in the final multivariable model (Table 3).

### Mealtime-specific distress

For mealtime-specific distress, univariable analysis demonstrated geographical location ( $P = 0.036$ ), tumour site ( $P < 0.001$ ) and the time during treatment when

*ScreenIT Carer* was completed ( $P < 0.001$ ) were significant factors associated with mealtime-specific distress (Table 2). Similar to general distress analyses, caring for a patient from a regional/rural location was a negative predictor of mealtime distress, whilst caring for a patient with a mucosal SCC and completing *ScreenIT Carer* later in treatment were identified as positive predictors of mealtime distress. Carer gender, relationship to patient and treatment type were not significant predictors of mealtime-specific distress (Table 2). All significant univariable factors remained significant predictors of carer mealtime distress in the final multivariable model (Table 3).

## Discussion

This study aimed to trial the use of a novel eCROM system, *ScreenIT Carer*, to monitor the pattern, prevalence and nature of carer-reported distress during (C)RT treatment for HNC. Overall, the uptake of the system by carers was variable. The majority of carers completed *ScreenIT Carer* intermittently during (C)RT, with only 18% of carers demonstrating full adherence to the use of the system as intended. Carer attendance at (C)RT treatment and associated appointments, and engagement with patients' care was not mandatory at the facility of study, which may have contributed to the variable engagement with the *ScreenIT* system. Furthermore, whilst weekly SMS reminders were provided to patients to complete *ScreenIT*, these were not specifically provided to carers which may have also compromised adherence. Despite the lower frequency of entries, the data provided by carers were relatively representative across the course of (C)RT, with 71% of carers providing data in both early and later treatment weeks. This suggests that the *ScreenIT Carer* system still provided a clinically viable and useful platform to monitor carer distress trajectories during/post-treatment. Further investigation is required to determine ways to improve carer engagement/adherence with eCROM systems, as well as to review the optimal frequency of data collection – to balance screening fidelity with carer burden.

Overall, the prevalence of general distress was high amongst carers, with more than half the cohort (58%) reporting a clinically significant level of distress at some point during/post-treatment. This high prevalence is in line with previous studies using traditional paper-based measurements, which have demonstrated that carers of patients with HNC experience significant levels of psychosocial distress as a result of their caring role.<sup>1,2,5</sup> Additionally, 46% of carers reported a clinically significant level of mealtime-specific distress at some time

**Table 2.** Univariable analysis of demographic factors for associations with carer general and mealtime-specific distress.

Variable	Regression coefficient (B)	Standard error	t	P
<b>General distress</b>				
Carer gender	0.504	0.315	1.60	0.110
Relationship to patient	-0.112	0.095	-1.18	0.237
Geographical location (patient)	-0.834	0.279	-2.98	<b>0.003</b>
Treatment type	0.730	0.351	2.08	<b>0.038</b>
Tumour site	0.218	0.086	2.52	<b>0.012</b>
Time when <i>ScreenIT Carer</i> was completed	0.355	0.258	1.38	0.169
<b>Mealtime-specific distress</b>				
Carer gender	0.527	0.329	1.60	0.110
Relationship to patient	0.005	0.099	0.05	0.961
Geographical location (patient)	-0.619	0.294	-2.11	<b>0.036</b>
Treatment type	0.538	0.368	1.46	0.144
Tumour site	0.399	0.089	4.50	<b>&lt;0.001</b>
Time when <i>ScreenIT Carer</i> was completed	1.269	0.263	4.82	<b>&lt;0.001</b>

Bold type indicates statistical significance  $P < 0.05$ .

**Table 3.** Multivariable model (GLM) for carer general and mealtime-specific distress.

Variable	Regression coefficient (B)	Standard error	z	P	Confidence interval	
					Lower bound	Upper bound
General distress						
Geographical location (patient)	-0.891	0.454	-1.96	0.050*	-1.781	-0.010
Treatment type	0.334	0.571	0.59	0.558	-0.785	1.454
Tumour site	0.935	0.415	2.25	<b>0.024</b>	-0.122	1.748
Mealtime-specific distress						
Geographical location (patient)	-0.775	0.230	-2.77	<b>0.006</b>	-1.324	-0.227
Tumour site	1.174	0.259	4.52	<b>&lt;0.001</b>	0.665	1.682
Time when <i>ScreenIT</i> Carer was completed	1.176	0.256	4.60	<b>&lt;0.001</b>	0.674	1.677

Bold type indicates statistical significance  $P \leq 0.05$ .

\*Trend where  $\geq 0.05$  but  $< 0.07$ .

during/post-treatment. This stands in concordance with findings from qualitative HNC literature that demonstrate the significant impact caring for someone with dysphagia can have on carer wellbeing.<sup>10,11,24</sup>

The prevalence of clinical distress ( $DT \geq 4$ ) peaked at week 4 of treatment for both general and mealtime-specific distress. This peak in clinical distress for carers may be related to increased burden of the caring role related to symptom management, practical support and the emotional response to seeing the patient impacted by treatment.<sup>8</sup> This finding may also be attributed, at least in part, to the delivery of the second round of high-dose cisplatin (received by 26% of patient cohort), which commonly requires increased contact with the health service, and higher toxicity acuity reported by patients with HNC. In the current study, the prevalence of severe distress was noted to gradually increase throughout the course of patient treatment, with the highest severity of distress ( $DT > 8-10$ ) being recorded at week 7 of treatment for both general and mealtime-specific distress. This peak in prevalence of severe distress aligns with the final week of radiotherapy and final cycle of chemotherapy and has been associated with the peak of severe acute toxicity.<sup>25</sup> It is also possible that the increase in severe carer distress was also impacted by carers feeling underprepared for post-treatment care duties when contact with the MDT commonly reduces. Research has highlighted that carers often feel unprepared for the persistent side-effects of dysphagia post-treatment and for undertaking HNC-specific care tasks, such as tracheostomy care and meal preparation.<sup>4,24</sup> These findings emphasise the need to address carer concerns throughout and beyond (C)RT treatment, in addition to supporting carers to feel prepared for the post-treatment recovery period. Furthermore, exploration of methods to intervene proactively with carers at particular time-points of patient treatment where higher levels of acute toxicity

are anticipated, as well as with carers exhibiting high distress in the early stages of treatment, is warranted, in an effort to potentially offset crises for carers and negative psychosocial outcomes in the longer term.

Despite the high prevalence of general and mealtime-specific distress, only 4.3% and 2.6% of *ScreenIT* Carer entries, respectively, requested a referral to specifically discuss their concerns. This disparity seen between distress prevalence and referral rates may be due to carer assumptions that supportive cancer care is primarily concerned with patient need, and consequently, carers may have low expectations of services and supports specifically available for them. Additionally, research suggests that carers often have a lack of awareness of the psychosocial impact associated with caring.<sup>5</sup> It is possible that the distress reported by carers in this study was perceived as a 'normal' or 'expected' experience that was anticipated, and therefore, referrals were not sought.

The secondary aim of this study was to determine if demographic or treatment factors influenced the severity of carer distress. Findings revealed that being and/or caring for a patient from a rural/regional location was associated with a lower incidence of general and mealtime-specific distress. This stands in contrast to a recent qualitative study investigating rural carers' experiences with cancer care, which demonstrated that rural carers faced significant challenges accessing cancer treatment for patients in metropolitan settings compared to their urban counterparts.<sup>26</sup> It is possible that the rural/regional participants in the present study may have temporarily relocated for treatment as a carer-patient dyad, thus reducing their distress. For example, through relocation rural/regional carers may have temporarily suspended other responsibilities (for example work or community roles) that may not have been possible for metropolitan carers. Lastly, it should be noted that it is common practice for regional/rural patients attending the



MSROS to have more comprehensive social work intervention built into their care in anticipation of the increased burden of being away from home, which may have reduced the severity of carer distress. The association between geographical location and carer distress requires further investigation in future research.

Finally, the time during treatment when *ScreenIT Carer* was completed was not found to be a significant predictor of general distress. This result was unexpected considering that research has demonstrated increased patient physical symptoms over the course of (C)RT to have a significant effect on carer psychological distress.<sup>1</sup> Conversely, mealtime-specific distress was significantly associated with time. This inconsistency may be explained by the individualised nature of distress trajectories over time. It could be hypothesised that the absence of pre-treatment mealtime-specific distress for carers, and the limited awareness of this potential impact to their function, may have resulted in a steeper increase in mealtime-specific distress across the cohort over time. Whereas for general distress, psychosocial response by carers may have been more overarching, and whilst the factors contributing to distress may have evolved, the severity of distress may have been less impacted by time. Further investigation exploring cohort trends and trajectories in a larger sample is warranted.

### Limitations

Some limitations to the present study are acknowledged. Firstly, the study relied on carers completing *ScreenIT Carer* throughout patient treatment; however, no specific processes were put in place to encourage adherence. Consequently, a large range in compliance with completing *ScreenIT Carer* was observed. It is possible that carers were only completing *ScreenIT Carer* when they felt distressed; therefore, the prevalence and severity of distress reported in the current study may be inflated. Secondly, in the current study, carer data were not triangulated with patient responses. Therefore, the study did not assess how patient responses on *ScreenIT* was affecting that of carers at the individual level. As per Badr *et al.*<sup>1</sup>, investigation of patient–carer dyad data in a larger project would be beneficial in the future. Finally, the level of interventional psychosocial support provided to carers (such as frequency of social work follow-up) was not collected as part of this study; therefore, there is potential for confounding as this may have influenced distress severity and trajectory over time. This is the focus of a subsequent study which is undertaking an in-depth analysis of the follow-up care pathway utilisation and outcomes for both patients and carers using *ScreenIT* to guide care.

### Conclusion

Carers of patients with HNC experience significant distress during (C)RT treatment. Carers identified both general and mealtime-specific distress to be multifactorial, with emotions and concerns related to patients' physical problems found to be the most common contributors to distress. Overall, this study highlighted that the use of an eCROM platform, such as *ScreenIT Carer*, is a feasible method to monitor clinically relevant alterations in carer psychosocial wellbeing during HNC treatment. The findings of this study underscore the importance of providing enhanced carer support in the (C)RT-HNC population.

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## Supporting Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

**Appendix S1.** NCCN distress thermometer modified problem list for carers (mealtime distress).

**Appendix S2.** *ScreenIT Carer*: risk management algorithms and care pathway.