

# Symptom management by a community palliative care team

Jürgen Abela

## Abstract

**Introduction:** The Malta Hospice Movement is a community palliative care team (CPCT) established in 1989. A service evaluation was carried out to check on reduction in physical distress for patients referred to the CPCT.

**Method:** During a period of ten weeks, all new cases referred for community palliative care services were included in the evaluation. A modified version of the Support Team Assessment Schedule (STAS) was used as a tool. The modifications done and symptoms inserted were informed by literature available on the frequency of symptoms in palliative care.

The version of STAS used in this particular evaluation is available on <http://www.kcl.ac.uk/schools/medicine/depts/palliative/qat/stas.html>. The modified STAS was delivered at referral, and subsequently every two weeks for a total of three assessments. The STAS was delivered by the *same* nurse.

**Results:** Of the 56 newly referred patients, 34 completed three assessments. The most common diagnosis was GIT cancer, while the most common reason of referral was “support”. There was a significant ( $1.7, p=0.039$ ) reduction in overall mean STAS scores, with non-significant reductions in individual item scores. Males exhibited greater score reductions than females. The symptom prevalence of patients remained unaltered throughout the evaluation.

**Conclusions:** There was reduction in physical distress for patients referred to the CPCT due to a variety of factors interacting at community level. However, symptom prevalence was unaltered. The results may be explained by the setting of care (community), lack of awareness of the present service to other stakeholders including family doctors and problems with access to relevant medications and out-of-hours cover.

## Keywords

Palliative care, community, service evaluation

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## Introduction

Palliative care can be defined as the holistic management of the patient and family/carers with the aim of improving the quality of life in patients with non-curable disorders.<sup>1</sup> According to the National Institute of Clinical Excellence there is a “...relative paucity of research evidence on many key topics”<sup>2</sup> in palliative care, which is due to the difficulty in carrying out research in this area of medicine.<sup>3-6</sup> An alternative tool that can be used to strengthen the evidence base of palliative care is service evaluation. Service evaluation looks at whether an existent service is justified and effective in reaching its stated objectives.<sup>7</sup>

A recent systematic review<sup>8</sup> showed a small positive effect when it came to hospital based palliative care teams. The number of studies addressing only community care is far less. However, it has been shown that community palliative care teams manage to decrease scores in many of the symptoms reported by patients<sup>9</sup>, whereas another study demonstrated that symptoms in the final week of life were relatively well controlled by community based teams.<sup>10</sup>

The community palliative service under evaluation was established in 1989. It is the only community palliative care service available in the Maltese islands, with a population of about 410,000. Up to the time of the present evaluation, this was the first instance that such an exercise was being performed.

## Methodology

### Selection of a tool

For this particular service evaluation, it was decided to use an evaluation tool instead of a structured interview with patients. A specific detailed symptom enquiry using a predefined list of symptoms in the tool is more suited for comparative analysis than a semi-structured interview where the patients volunteer symptoms themselves.<sup>11</sup>

A list of desirable characteristics used frequently in assessing various other audit tools was drafted to facilitate the choice of the evaluation tool.<sup>12,13</sup> Subsequently a literature search was carried out. The databases employed were Medline, Embase and Cinahl and the search was restricted to the period 1990-2008. The key words used included “palliative care”; “evaluation” and “audit.” Table 1 summarises the results of the search, and as can be seen, when compared with other commonly used assessment tools, the Support Team Assessment Schedule (STAS) was the only tool that met all of the set criteria.

**Table 1:** Comparison of Different Evaluation Tools

Tool	Desirable Characteristics				
	Reliable & Valid	Quick & easy to complete	Used in the community	Can be completed by Staff	Holistic assessment of physical distress
EFAT	+	+	-	+	-
SDS	+	+	-	+	-
ESAS	+	-	-	-	-
CAMPAS	-	-	+	+	+
POS	+	+	+	+	-
Rott. Checklist	+	-	-	+	-
STAS	+	+	+	+	+

Key: EFAT – Edmonton Functional Assessment Tool; SDS – Symptom Distress Scale; ESAS – Edmonton Symptom Assessment Scale; CAMPAS – Cambridge Palliative Audit Schedule; POS – Palliative Outcome Scale; Rott. Checklist – Rotterdam Checklist; STAS – Support Team Assessment Schedule

### **Support Team Assessment Schedule (STAS)**

STAS was purposely developed for teams to evaluate their care services. This tool has been extensively validated, used in different settings and has even been translated into several languages.<sup>14-17</sup> The STAS consists of a questionnaire using a 0-4 Likert scale on various themes pertaining to palliative care including pain, spirituality, psychological and financial issues. In total there are 17 questions. A modified version of STAS has been used for this evaluation, which is available at <http://www.kcl.ac.uk/schools/medicine/depts/palliative/qat/stas.html>. It is not uncommon to modify STAS.<sup>18</sup> The focus of this evaluation is the management of physical distress. STAS contains a number of items which are not strictly related to physical distress. Hence some questions e.g. financial issues were excluded. Items concerning spirituality, though admittedly relevant in physical distress, were also omitted since it was felt that the majority of the Maltese population is not appreciative of the distinction between spirituality and religiosity. This has also been found to be an issue in other staunchly Catholic countries such as Italy.<sup>19</sup>

Since the focus of this project is the reduction in physical distress of patients, it was felt that the second question was neither specific nor sufficiently detailed. STAS divides symptomatology into two broad categories, namely pain and other symptoms. With respect to the latter, different symptoms are grouped under this single question and some of them are as diverse as nausea and dyspnoea. Hence the second question was substituted and expanded into questions on individual symptoms as suggested in McKee's expansion of the core STAS audit tool.<sup>20</sup> The list of symptoms has been adapted from The Palliative Care Assessment (PACA) tool<sup>21</sup> and includes:

- Dyspnoea
- Nausea
- Anorexia
- Oral discomfort
- Constipation.

These symptoms were chosen since they are particularly prevalent in the palliative care scenario.<sup>22,23</sup>

### **Adopted procedure**

A protocol was set-up to establish how this evaluation should proceed. Every effort was made to encourage ownership, by the staff, of this evaluation process.<sup>24,25</sup> In addition, the SPREE framework (small, plan, regular, exchange, enjoy) was kept in mind while carrying out the evaluation.<sup>26</sup> Consequently, the following measures were adopted:

- Adequate notice was given to all staff prior to the commencement of the actual process, following approval from the management.
- A discussion group was carried out. Feedback was sought via a SWOT (strengths, weaknesses, opportunities and threats) analysis.
- Each nurse carried out a pilot assessment a few weeks before the actual evaluation, both as practice as well as to allow enough time to iron out teething problems. This also gave the author some insight on the scores involved.

Since the nurse acts as the key worker, carrying out the primary assessment of the patient on referral and presenting the case to the rest of the team, it was felt that the nurses were in the best position to deliver the STAS. STAS was delivered at the primary assessment, and following that, every two weeks for the first month after referral. It is important to note, that the **same** nurse delivered each STAS. This was encouraged in order to decrease inter-observer bias and increase credibility of findings. The two week period was chosen after reviewing the literature available.<sup>12,18</sup> Given the community setting, where coordinating interventions is much more difficult and time-consuming when compared to an in-patient setting, the two week interval was deemed more appropriate than a shorter one.

Ethical approval was obtained from the University of Malta Research Ethics Committee. Data was analysed using SPSS version 15.0, while data was compiled using Excel.

### **Results**

During the service evaluation, 56 patients were referred as new cases. Thirty one (55.4%) patients were male, whereas 25 (44.6%) were females. The mean age was 69.2 years.

Figure 1 illustrates the flow of patients during the service evaluation and the total number of patients completing STAS measurements. A total of 139 assessments were completed. Five assessments were refused since the patients declared that they were feeling well and did not need review.

Table 2 outlines the range of diagnoses for all 56 patients involved in the service evaluation. The most common diagnosis for the referred patients was gastrointestinal (GIT) cancers (35.71%), followed by respiratory and Intrathoracic cancers (14.29%). Breast cancer was third most common with 12.50%.

**Table 2: Frequency of diagnosis**

Diagnosis	Frequency	Percent
Gastrointestinal Tract (GIT)	20	35.7
Respiratory and Intrathoracic	8	14.3
Breast	7	13.0
Male Genital Organ	4	7.0
Brain and Spinal Cord	4	7.0
Lymphoid and Haemopoietic Tissue	4	7.0
Others	4	7.0
Female Genital Organs	3	5.4
Lip, Oral cavity and Pharynx	1	1.8
Motor Neurone Disease	1	1.8
<b>Total</b>	<b>56</b>	<b>100</b>

**Table 3: Reason for referral**

Reason for referral	Frequency	Percent
Support	25	44.6
Palliative Care	3	5.4
Equipment	8	14.3
Equipment & Support (when quoted together; not the sum of 1 & 3)	12	21.4
Palliative Care & equipment (when quoted together; not the sum of 2 & 3)	1	1.8
Uncontrolled symptoms	3	5.4
Other	3	5.4
<b>Total</b>	<b>55</b>	<b>98.2</b>
Absent/not written down	1	1.8
<b>Grand total</b>	<b>56</b>	<b>100</b>

Table 3 lists the reasons why patients were referred to community palliative services. The most commonly cited reason was "support." This is an umbrella term, which was used in the referrals to loosely include "home support", "support to family", "emotional support" and "patient support." Another commonly cited reason was provision of various aids and equipment to help the management of patients in the community.

#### Analysis of STAS scores

The STAS scores were analysed according to the following scheme:

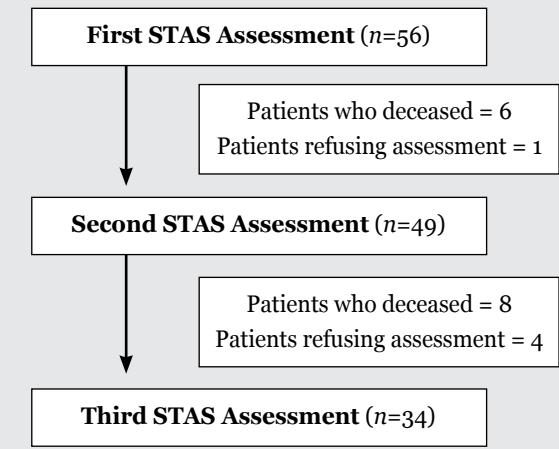
- *Total mean scores (Table 4)*

Two-tailed parametric t-tests were used to compare score means. There was a significant reduction from the first STAS mean to the third STAS mean (1.7,  $p=0.039$ ).

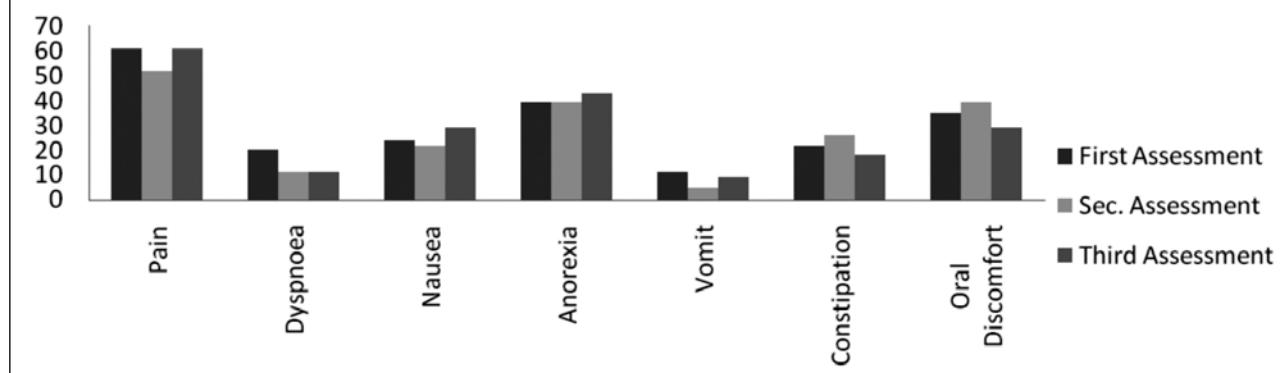
- *Symptom Prevalence and Individual Item scores (Figure 2 & 3)*

A symptom was regarded as being present if the STAS score was greater than zero. The most prevalent symptom at primary assessment was pain. The presence of symptoms was more or less constant, in contrast to the individual item scores (Figure 4), where there is a clear drop in scores between the first and last assessment in most cases, though this failed to reach statistical significance.

**Figure 1: Flow of patients during the evaluation**



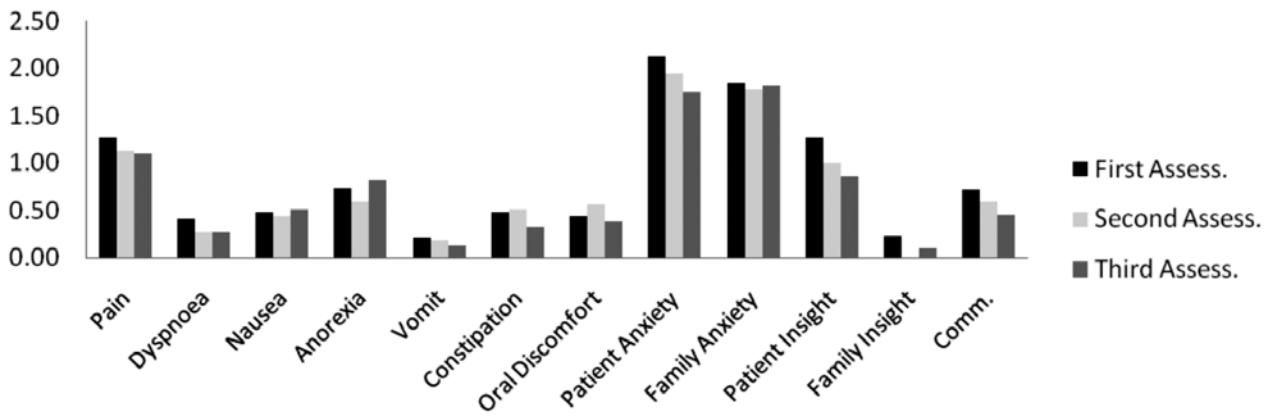
**Figure 2: Prevalence of symptoms along the assessments for the 34 patients who completed all three assessments**



**Table 4:** Reduction in mean STAS scores

Compared STAS Assessments	Number of Patients	Means	Difference in Means	95% Confidence Interval	P Value
First – Second	49	9.69 – 9.18	0.51	-1.05 – 2.07	0.514
Second – Third	34	8.71 – 8.24	0.47	-1.15 – 2.10	0.558
First – Third	34	9.94 – 8.24	1.70	0.89 – 3.32	0.039

**Figure 3:** Individual Item Scores along the assessments. Comparison valid only for the 34 patients completing all three STAS scores



- Variations of STAS scores related to gender (Figure 4)

Score reduction for males was statistically significant (3.27,  $p=0.029$ ), whereas females showed a smaller reduction which was non-significant (0.47,  $p=0.597$ ).

## Discussion

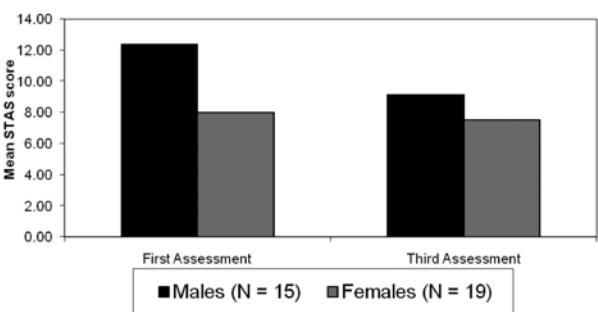
The following discussion is divided into four sections. The first section deals with the characteristics of the population studied, the second section addresses symptom prevalence, the third section focuses on STAS scores, while the final section considers the strengths and limitations of the study.

### Demographic characteristics

The total number of patients referred during this period was 56, but only 34 patients managed to complete three STAS assessments. This high attrition rate is symbolic of palliative care research.<sup>27,28</sup> Unfortunately, due to time pressure and the limited human resources available, the study could only be carried out for two months, thereby limiting the number of patients involved.

The demographic profile, with respect to sex and age, of the population referred to community palliative care services, is similar to that of other studies.<sup>12,29</sup> The spectrum of diagnoses of the population under study is similar to other studies<sup>30</sup> with GIT cancer (35.71%) being the most common diagnosis. It must be stated that cancers with the highest prevalence are lung and breast cancers. GIT cancer is an umbrella term which encompasses different cancers and when added together surpass lung or breast cancer.

**Figure 4:** Reduction in STAS scores according to sex



### Symptom prevalence

In this evaluation, the symptom load, or prevalence of symptoms seems to be consistent with other studies.<sup>23</sup> The frequency of symptoms reported depends on four factors.<sup>28</sup> These four factors will be used for further analysis.

**Setting of care:** Different levels of treatment may be provided to control symptoms according to care setting, resulting in differences in symptom prevalence between care settings.<sup>23</sup> It can be argued, that the caring environment, continuous supervision and also support provided by an in-patient unit as opposed to the situation in the community, will almost certainly influence the frequency and distribution of symptoms. In addition, the setting of care may influence results since it facilitates increasing frequency of delivery of the evaluation tool.

**Assessment tools:** It is important to point out that symptoms such as “weakness” and “weight loss” are not listed in the STAS questionnaire, despite being amongst the most common symptoms in a community setting.<sup>23</sup> These symptoms are particularly difficult to manage, and their absence in the assessment tool may well have influenced the STAS scores.

**Study design:** The present study was a service evaluation of one particular community palliative care service. A different approach might have yielded different results. Study design can be seen to influence results in two major ways – either via the tool used, or via the number of patients or centres involved. For example, if the Edmonton Symptom Assessment Tool (ESAT) were used, the evaluation would have focused on symptoms scores, eliminating confounding factors such as the “non-physical” items present in STAS.

**Different cancer types:** It is a well known fact that morbidity in cancer patients depends also on the cancer type.<sup>31,32</sup> However, the profile of diagnoses in this study is comparable to other cohorts, and as such not a significant issue in the interpretation of results. Symptom prevalence is also a result of the disease process itself. Interventions provided to reduce physical distress are not uniquely responsible for increase/decrease in symptom severity/reduction.

### **STAS scores**

The successive mean STAS scores for the patients completing all three assessments clearly show a significant, albeit small reduction in scores, in line with other studies.<sup>8,9</sup> The percentage of patients reporting symptoms remained rather stable. In the literature, there are contrasting views on symptom prevalence in palliative care, with some studies concluding that symptom frequency increases towards death<sup>33</sup>, while others report a variation in progression.<sup>28,30</sup> Most of these studies followed patients till their demise, and hence comparison with this evaluation is not appropriate.

Thus patient referred to the CPCT under review had a stable symptom load but a reduction overall STAS scores. This paradoxical situation can be due to any of the four factors outlined in the previous section. The setting of care, in particular, probably plays an important role, since treatment options are more restricted. Indeed “symptoms such as dyspnoea or massive bleeding are more easily managed in the hospital.”<sup>33</sup> In addition, the organization of the local health system does not allow sufficient access to secondary care resources from the community in order to achieve optimum symptom control.

The importance of the assessment tool (STAS) in interpreting results has been highlighted previously. With regards to the paradox observed between STAS score reductions and unrelenting symptom prevalence, one could argue that the absence of asthenia and weight loss from STAS may have artificially inflated the reductions in overall STAS scores, given the well known difficulty in effectively treating these two symptoms. Another possible explanation for the above

mentioned paradox could be the contribution of the non-physical items to the overall STAS score. Nearly all non-physical items showed substantial individual item score reductions, particularly the patient insight item. These reductions contribute to the overall STAS reductions, but are foreign to the actual reduction in the physical distress items.

A final possible explanation lays in the misconceptions which GPs and hospital based specialists may have of the community palliative care team members. As seen by outsiders, there may be a lack of definition of what the team members, including nurses and doctors do, which may contribute to underutilisation or wrong utilisation of our resources. This situation has been clearly documented in the literature.<sup>34,35</sup>

An interesting feature of the individual item scores is the persistently higher scores for patient insight when compared to family insight. The reason for such phenomenon can be seen in the Mediterranean culture of “covert” working, in that the family could exert pressure on professionals to withhold information regarding diagnosis or prognosis from the patient in the belief that such information can be harmful to the patient.<sup>19,36</sup>

Male patients were observed to have greater score reductions overall when compared to female patients. This dichotomy is interesting and possibly supported by the literature. In fact, females exhibit higher levels of fatigue than male patients, while male patients tend to do better with control of gastrointestinal symptoms.<sup>37,38</sup> A possible explanation for such difference in response can be found by referring to the grief models of Stroebe and Schut.<sup>39</sup> Males tend to adopt “restoration focused” mechanisms as opposed to females who adopt a “loss focused” mechanism. One could postulate that this model can be applied in the dimension of symptom control, and would effectively explain the above observations.

### **Strengths and limitations**

A particular strength of this study lies in the fact that all new cases referred during a particular point in time were included, thus eliminating bias. A widely used, validated and reliable assessment tool (STAS) was used for the study, with some modifications. Paradoxically, this same tool can also be seen to be a possible confounding source of the results. STAS does not list “weight loss” or “fatigue.” These symptoms are very difficult to address, and their omission from the questionnaire could have lead to an artificial accentuation of score reduction. In addition, though the “non-physical” items are important, the fact that symptom prevalence did not decrease may imply that after all, overall STAS reductions were statistically significant due to the contribution of these “non-physical” item scores.

There is a variety of factors interacting at community level. These include the actual members of the CPCT, GPs, hospital doctors and the patients’ carers. Trying to dissect which force is responsible for the results is quite difficult. Certainly the CPCT contributes significantly to this equation. One can thus conclude that the sum of these factors actually reduces the physical distress of patients.

Despite including all new cases, the evaluation process took place during a particular period of the year, and this could have influenced the conclusions of the study. Unfortunately the robustness of the results is undermined by the small number of patients enrolled and the high attrition, which nearly reduced the patient pool by a third. In the future, this could be addressed by prolonging the period over which new patients are accrued to the study, which would increase the total patient pool as well as provide larger duration of follow-up.

## Conclusion

In summary, patients referred to the CPCT under evaluation had reduction in STAS scores, non-significant reduction in individual item scores and a stable symptom load. Hence there is reduction of the physical distress of patients, but there is room for improvement.

This was the first ever evaluation of a community palliative care service locally. The study should hopefully help to establish this specialty at a local level and contribute locally to the propagation of audit and evaluation philosophy, even outside palliative care. Future (and possibly larger) evaluations are planned to assess whether changes triggered by this study will effectively improve the care of patients.

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## Conflict of interests

The author is the medical officer of The Malta Hospice Movement (TMHM). Authorization from the council of TMHM was granted for such evaluation. No additional funding was provided.

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