

School of Health & Life Sciences

A CRITICAL INVESTIGATION OF THE OUTCOMES OF THE TRADITIONAL MODEL OF SPECIALIST PALLIATIVE DAY SERVICES ON SPECIFIC COMPONENTS OF ATTENDEE QUALITY OF LIFE, WELLBEING AND MOOD:

A Mixed Methods Study

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BACKGROUND

Specialist Palliative Day Services (SPDS) have been in existence in the United Kingdom (UK) since the mid-1970s and are traditionally provided by larger hospice organisations (Stevens, 2009: 2014; Wilkes, et al., 1978). In keeping with the central tenet of palliative care the outcome of SPDS is the promotion of quality of life (World Health Organisation 2018: Hearn and Myers, 2001). While there is reasonable evidence to demonstrate the structures and processes of such services there is little evidence of their effectiveness and efficiency (Stevens, et al., 2011). Consequently, this study investigated the outcomes of the traditional model SPDS on specific components of quality of life already considered to be outcomes on such services.

RESEARCH APPROACH AND QUESTIONS

This was a two phase, convergent mixed methods research (MMR) study. Phase 1 utilised the EQ5D-3L, Rosenberg Self-esteem Scale (RSES), the death acceptance (DA), goal seeking (GS), and choice (CR) subscales of Life Attitude Profile-Revised (LAP-R), the purpose and meaning composite scale of the LAP-R and the Hospital Anxiety and Depression Total Mood Scale (HADST) to measure components of quality of life over 20 weeks. Phase 2 utilised emotional touchpoint interviews to elicit attendees' perceptions of attending SPDS. In keeping with a convergent MMR approach three research questions were developed to meet the overall aim of the study (Creswell, 2015). **Figure 1** outlines the approach and the research questions.

DATA ANALYSIS AND FINDINGS

Quantitative data were analysed by employing descriptive statistical tests in SPSS. Qualitative data were subjected to thematic analysis using Braun and Clarke's (2006) framework. In keeping with a convergent MMR approach both data sets were then combined, scrutinised and triangulated (figure 1). A data integration matrix was then developed to demonstrate where data was related and the level of congruence that was achieved. **Table 1** highlights the findings and their congruence.

QUALITATIVE THEMES 15 INTERVIEWEES	QUANTITATIVE OUTCOME MEASURES BASELINE - 21 PARTICIPANTS WEEK 20 - 13 PARTICIPANTS	CONVERGENCE	DIVERGENCE	PARTIAL AGREEMENT	SILENCE
I'm not sure if this is for me Death anxiety at point of referral was spoken about as a reason not to attend.	LAP-R: DA sub-scale Death anxiety at point of referral was only evident in a few participants.			*	
I'm not sure if this is for me Death anxiety dissipated after first visit as the interviewee got used to the service and the other people.	LAP-R: DA sub-scale Data at this crucial stage was not captured.				*
I'm not sure if this is for me There was a recognised need to become used to people who die in the group to continue attendance.	LAP-R: DA sub-scale Death anxiety remained an issue for a small number of participants over the study period.	*			
Being with friends like me Being in the same boat with people with similar issues engendered feelings of being understood, valued, trusted, respected and better off than others.	RSES Self-esteem mean scores were within normal range on admission and remained so over the data collection period for all but one participant whose self-esteem was constantly low.	*			
I am able to take part in things I like Being given a choice of what to do at each visit engendered feelings of being valued and respected.	LAP-R CR Sub-scale Mean scores were lower than normative and weakened over time. There was wide variation within participant scores.		*		
I am able to take part in things I like Some interviewees reported trying new things, while others were content remaining in the in-group.	LAP-R GS Sub-scale Mean scores were lower than the norm and individual participant scores for goal seeking varied within over the study period. Optimal goal seeking tendencies and meaning in life (MiL), overall health status and normal mood were correlated.		*		
I am able to take part in things I like Some interviewees took part in activities and interventions which engendered feeling of success and being able to give something back.	The outcomes of these observations cut across all the outcomes measures being utilised and thus will be discussed in terms of overall wellbeing.				*
I feel so well cared for Interviewees reported feeling as well as they could be but acknowledged that this varied over time.	EQ5D-3L single items: Mobility Means scores remained at mid-range for duration of study period with no variation. EQ5D-3L single items: Self-care Means scores remained at mid-range for duration of study period with no variation. EQ5D-3L single items: Usual Activities Means scores remained at mid-range for duration of study period with no variation. EQ5D-3L single items: Pain/discomfort Means scores remained at mid-range for duration of study period with no variation. EQ5D-3L single items: Anxiety and Depression Means scores remained at mid-range for duration of study period with no variation.			*	
I feel so well cared for Illness concerns were taken seriously by the trusted SPDS team who worked with interviewees as themselves to minimise their issues and to deal with any unexpected problems that arose from time to time. This improved their feelings of safety and security and overall wellbeing.	EQ5D-3L Overall Health Status VAS Mean scores were lower than the normative mean and for some remained so over the duration of the study period for some. Health status varied across participants. Overall health status, optimal MiL and goal seeking tendencies and normal mood were correlated.			*	
It's different from anything else I do Attending SPDS was reported to fill a gap in current life events. As attending was a regular occurrence it was reported that it gave interviewees purpose and coherence in their lives.	LAP-R PMI Composite Scale The mean scores stayed around the normative mean. For a small number of participants MiL remained low across the study period. Optimal MiL and goal seeking tendencies, overall health status and normal mood were correlated.			*	
It's different from anything else I do Interviewees reported that they were allowed to have fun in SPDS which lifted their spirits and engendered pleasure and laughter.	HADST The mean scores remained within the normal range over the study period. A small number of participants experienced low mood across the study period. Normal mood, optimal MiL and goal seeking tendencies and overall health status were correlated.			*	
Support my family A small number of interviewees reported that attending SPDS helped their families through time off from caring and improved relationships.	Exploring the benefits of SPDS on family wellbeing was not an aim of this study and was not measured in Phase 1.				*

Table 1: Data Integration Matrix: Findings and Congruence.

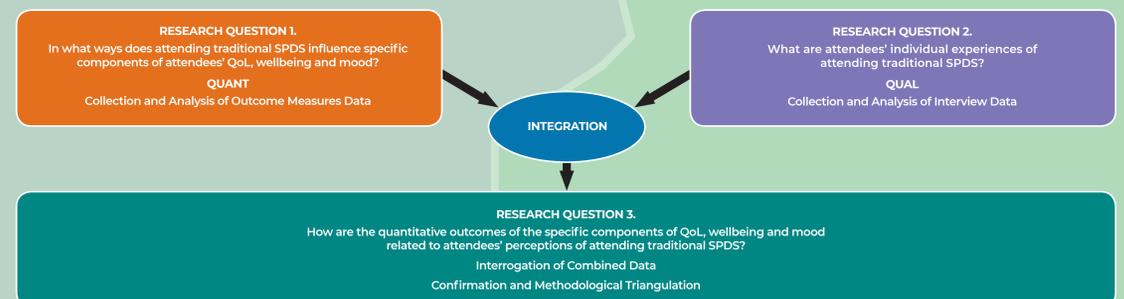


Figure 1.

CONCLUSIONS AND RECOMMENDATIONS

This appears to be the first MMR study to critically investigate the outcomes of attending the traditional model of SPDS. Examining the phenomenon from two separate viewpoints allowed SPDS to be scrutinised in a way that would not have been possible had the quantitative and qualitative findings not been interrogated and discussed as a whole. The conclusions and recommendations from this study are outlined below.

- Referral to SPDS generates death anxiety and may be experienced throughout attendance at SPDS. Services should acknowledge death anxiety as potential cause of non-attendance and work more closely together with public health to reduce the reticence to attend. SPDS should promote themselves through digital technology to allow potential attendees to see the benefits of attending at the point of referral. Assessment of death anxiety within SPDS is required to promote optimal quality of life. Further research on death anxiety and how this affects people with advanced illness is necessary.
- Normal self-esteem may be maintained in SPDS by enabling people in similar circumstances become a valued member of an in-group. SPDS should promote and nurture such groups to allow attendees to benefit from peer support and to feel normal. SPDS should consider incorporating in-groups into their service provision. Further research on the benefits of peer support would be advantageous.
- Attending SPDS allows people to take part in a range of activities and interventions which promote self-management, learning, fun and achievement. SPDS should consider the development of a whole-person rehabilitative framework in which self-management and occupational balancing techniques are promoted. SPDS need to provide evidence of the intended outcomes of activities and interventions to clarify how specific aspects of SPDS benefit attendees and promote quality of life. Further MMR should explore the outcomes of specific SPDS activities and interventions on quality of life.
- Attending SPDS gives meaning, purpose and structure to the lives of some attendees. SPDS should assess existential wellbeing through meaning in life using an outcome measure such as the LAP-R PMI in conjunction with an assessment interview. Further research on how structure and meaning in life enhance the quality of life in SPDS attendees is required.
- Mood was normal for most attendees on admission to SPDS and this did not vary over time. Due to the individuality of responses to illness SPDS should proactively assess mood using a robust tool such as the HADST on a regular basis. Further research on how mood affects attendance at SPDS is required.
- Being able to make choices within SPDS did not impact on overall choice and control in life. SPDS need to assess choice and control in attendees and employ interventions that help them feel in choice and control in their lives. Further exploration of interventions such as mindfulness which promote choice and control would be valuable. Research into the role of choice and control in people with advanced illness is required.
- Variance in individual health status is due to the effect of advanced illness on all domains of their quality of life. Further utilisation of SPDS could increase access to an expert whole-person care approach which maintains quality of life, wellbeing and mood of with advanced illness. SPDS should ensure they have available the requisite expert team to provide this specialist level of care and support to ensure the holistic needs of people with advanced illness are addressed.
- Quantitative measurements do not fully explain the subjective experience of attending SPDS and it is recommended that the use of Emotional Touchpoint interviews should be used to supplement such data to add to the body of evidence. MMR is recommended as the most appropriate way to further research the outcomes of SPDS.

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