

Developing and Evaluating a Psychological Intervention for use in Palliative Care

Submitted by John Melvin Galfin to the University of Exeter

as a thesis for the degree of

Doctor of Philosophy in Psychology

in May 2011

This thesis is available for Library use on the understanding that it is copyright material and that no quotation from the thesis may be published without proper acknowledgement.

I certify that all material in this thesis which is not my own work has been identified and that no material has previously been submitted and approved for the award of a degree by this or any other University.

Signature: 

ABSTRACT

As a GWR research project joint funded by Hospiscare, the main objective of this research was to examine the nature of psychological distress in palliative care, with the specific purpose of developing and evaluating accessible psychological interventions suitable for Hospiscare staff to use with clients.

There is evidence that palliative care patients and their caregivers experience psychological difficulties including (a) studies of depression and anxiety in palliative care; (b) the concerns expressed by palliative care patients and their caregivers. However, the studies are generally qualitative in nature based on interviews of small samples of participants. Therefore, Study 1 and Study 2 adopted a cross-sectional design to examine psychological distress and rumination in samples of palliative care patients, their caregivers and an age-matched control group. The results from Study 1 and Study 2 indicated that psychological distress and rumination on existential concerns were elevated in palliative care patients and their caregivers. Furthermore, findings suggested an association between psychological distress and abstract rumination.

Study 3 reported a case series piloting an intervention developed from concreteness training (CT) designed to address abstract rumination in palliative care. The case series indicated that with some modification to the identification and screening of patients, the treatment could be acceptable and feasible for palliative care patients.

Study 4 examined the effectiveness of the CT guided self-help intervention in a randomized controlled trial. Findings indicated that the intervention could be effective for reducing anxiety, but not depression in palliative care patients. Moreover, Study 5's findings also raised the possibility that abstractness was a partial mediator of the effects of the intervention on self-reported symptoms of anxiety in palliative care patients.

Study 5 utilised a cluster randomized controlled design to evaluate a training programme designed to teach hospice staff how to deliver the CT guided self-help intervention. Results indicated that there was a more positive impact of routine care on patient distress for nurses attending training, when compared to nurses not attending the training. However, the training did not impact on nurses' self-reported confidence or behaviour in addressing patients' distress.

TABLE OF CONTENTS

<u>ABSTRACT</u>	<u>2</u>
<u>ACKNOWLEDGEMENTS</u>	<u>4</u>
<u>STATEMENT OF THE CANDIDATE'S CONTRIBUTION TO CO-AUTHORED PAPERS</u>	<u>5</u>
<u>STATEMENT OF THE SUPERVISORS' CONTRIBUTION TO CO-AUTHORED PAPERS</u>	<u>7</u>
<u>CHAPTER 1: INTRODUCTION</u>	<u>19</u>
1.1 <u>Definition of palliative care</u>	<u>19</u>
1.2 <u>Levels of psychological distress in palliative care patients</u>	<u>21</u>
1.3 <u>Practical drivers for research</u>	<u>26</u>
<u>Psychological issues in palliative care</u>	<u>28</u>
2.1 <u>Psychological distress in palliative care</u>	<u>29</u>
2.1.1 <u>Definition of depression</u>	<u>29</u>
2.1.2 <u>Definition of anxiety</u>	<u>32</u>
2.1.3 <u>Methods of assessing prevalence of depression and anxiety in palliative care patients</u>	<u>35</u>
2.1.4 <u>Rates of diagnosis of depression and anxiety in palliative care patients</u>	<u>37</u>
2.1.5 <u>Prevalence of depression and anxiety in carers of palliative care patients</u>	<u>40</u>
2.1.6 <u>Concerns expressed by palliative care patients</u>	<u>41</u>
2.1.7 <u>Concerns expressed by carers of palliative care patients</u>	<u>45</u>
2.1.8 <u>Limitations of studies identifying concerns in palliative care</u>	<u>46</u>
<u>Conclusion for Section 2.1.</u>	<u>47</u>
2.2 <u>Implications of psychological distress in palliative care</u>	<u>48</u>
2.2.1 <u>Impact of psychological distress on physical symptoms</u>	<u>48</u>

2.2.2	<u>Relationship between psychological distress and emotional wellbeing</u>	49
2.2.3	<u>Impact of psychological distress on quality of life</u>	50
2.2.4	<u>Impact of psychological distress on desire for hastened death</u>	50
2.2.5	<u>Impact of psychological distress for carers of palliative care patients</u>	52
	<u>Conclusion for Section 2.2.</u>	53
2.3	<u>Issues in assessment and treatment of psychological distress in palliative care</u>	
		53
2.3.1	<u>Assessment of psychological distress in palliative care</u>	54
2.3.2	<u>Psychological interventions for palliative care patients</u>	55
2.3.3	<u>Psychological interventions for carers of palliative care patients</u>	66
2.3.4	<u>Pharmaceutical interventions in palliative care</u>	68
2.3.5	<u>Accessibility and availability of psychological interventions in palliative care</u>	
		70
	<u>Conclusion for Section 2.3.</u>	71
2.4	<u>Rumination and distress in palliative care</u>	72
2.4.1	<u>Rumination</u>	72
	<i><u>Prospective longitudinal studies</u></i>	74
	<i><u>Experimental studies</u></i>	75
2.4.2	<u>Theoretical rationales for rumination in palliative care</u>	77
2.4.3	<u>Empirical evidence of rumination in palliative care</u>	79
	<u>Aims of Research</u>	82
 <u>CHAPTER 2: PSYCHOLOGICAL DISTRESS, RUMINATION, AND COPING IN</u>		
<u>PALLIATIVE CARE</u>		85
<u>Additional literature review</u>		86

<i>Coping strategies utilised by palliative care patients</i>	86
<i>Coping strategies utilised by carers of palliative care patients</i>	90
<i>Effectiveness of coping strategies utilised by of palliative care patients and their caregivers</i>	91
Research Article (Published in Journal of Palliative Medicine): “Psychological Distress and Rumination in Palliative Care Patients and their Caregivers.”	94
<i>Abstract</i>	94
<i>Introduction</i>	95
<i>Methods</i>	97
<i>Participants</i>	97
<i>Procedure</i>	98
<i>Results</i>	99
<i>Psychological Distress</i>	99
<i>Concerns</i>	100
<i>Rumination</i>	101
<i>Intercorrelations between concerns, rumination, and psychological distress</i>	102
<i>Discussion</i>	103
Further Investigations and Analysis	105
<i>Quality of life measure</i>	105
<i>Coping Interview</i>	106
Supplementary Results	107
<i>Quality of life</i>	108
<i>Coping strategies</i>	109
Extended discussion	111

<u>CHAPTER 3: CONSTRUAL LEVEL, RUMINATION, AND PSYCHOLOGICAL</u>	
<u>DISTRESS IN PALLIATIVE CARE</u>	<u>114</u>
<u>Expanded literature review</u>	<u>115</u>
<u><i>Construal level theory</i></u>	<u>115</u>
<u><i>Elaborated control theory</i></u>	<u>118</u>
<u>Research Article (Accepted for publication in Psycho-oncology): “Construal level,</u>	
<u>rumination, and psychological distress in palliative care.”</u>	<u>121</u>
<u><i>Abstract</i></u>	<u>121</u>
<u>Introduction</u>	<u>122</u>
<u>Method</u>	<u>124</u>
<u><i>Participants</i></u>	<u>124</u>
<u><i>Procedure</i></u>	<u>124</u>
<u><i>Measures</i></u>	<u>124</u>
<u><i>Rumination Interview</i></u>	<u>125</u>
<u>Results</u>	<u>126</u>
<u>Discussion</u>	<u>129</u>
<u>Further details on methods and expanded discussion</u>	<u>131</u>
<u><i>Uncertainty</i></u>	<u>131</u>
<u><i>Abstractness</i></u>	<u>131</u>
<u>More extensive discussion of findings</u>	<u>132</u>
<u>CHAPTER 4: CASE SERIES</u>	<u>137</u>
<u>Introduction</u>	<u>137</u>
<u>Method</u>	<u>142</u>

<u>Design</u>	142
<u>Participants</u>	142
<u>Training intervention</u>	143
<u>Materials</u>	144
<u>Procedure</u>	145
<u>Results</u>	145
<u>Group results</u>	145
<u>Individual Cases</u>	146
<u>Participant 1</u>	148
<u>Participant 2</u>	149
<u>Participant 3</u>	150
<u>Participant 4</u>	152
<u>Participant 5</u>	153
<u>Participant 6</u>	154
<u>Discussion</u>	155

CHAPTER 5: A PILOT RANDOMIZED CONTROLLED TRIAL OF GUIDED SELF-HELP INTERVENTION. 159

Research Article (Accepted for publication in Palliative Medicine): “A brief guided self-help intervention for psychological distress in palliative care patients: a randomized controlled trial.” 161

<u>Abstract</u>	161
<u>Introduction</u>	162
<u>Methods</u>	166
<u>Procedure</u>	166

<i>Participants</i>	167
<i>Interventions</i>	170
<i>CT guided self-help</i>	170
<i>Materials</i>	171
<i>Analysis</i>	172
Results	173
<i>Anxiety</i>	173
<i>Depression</i>	174
<i>Quality of Life</i>	174
Discussion	176
Supplementary Material: Further details, investigations and analyses	180
<i>Recruitment</i>	180
<i>Abstractness interview</i>	180
Supplementary Results	181
<i>Abstractness</i>	181
<i>Mediational analysis</i>	181
Further discussion on mechanism of the treatment effect	183
<u>CHAPTER 6: AN EVALUATION OF A TRAINING PROGRAMME TO TEACH A BRIEF</u>	
<u>GUIDED SELF-HELP INTERVENTION TO HOSPICE STAFF.</u>	
	185
Expanded literature review	186
<i>Brief workshop-based training</i>	186
<i>Extended training programmes</i>	187
<i>Training palliative care staff</i>	190

Research Article (Published in International Journal of Palliative Nursing): “An evaluation of a training programme to teach a brief guided self-help psychological intervention to hospice staff”.

194

<i>Abstract</i>	194
<u>Introduction</u>	195
<u>Methods</u>	198
<i>Design</i>	198
<i>Procedure</i>	198
<i>Nurse Teams</i>	199
<i>Absorption Guided Self-help Intervention</i>	199
<i>Training Programme</i>	200
<i>Materials</i>	200
<i>Psychological Outcomes: caseload</i>	201
<i>Analysis</i>	202
<u>Results</u>	202
<i>Psychological Outcomes: caseload</i>	202
<i>Participant behaviour and confidence</i>	203
<u>Discussion</u>	206
<u>Further analyses</u>	209
<i>Matched samples.</i>	209
<i>Non-parametric analysis</i>	211
<u>Further discussion</u>	213
<i>Further limitations of study</i>	213
<i>Treatment effect</i>	213
<i>Lack of implementation of the intervention</i>	214

<u>CHAPTER 7: GENERAL DISCUSSION</u>	<u>216</u>
<u>Overview</u>	<u>216</u>
<u>Summary and implications of main findings</u>	<u>221</u>
<u><i>Understanding psychological distress in palliative care</i></u>	<u>221</u>
<u><i>Assessment and treatment of psychological distress in palliative care</i></u>	<u>222</u>
<u><i>Rumination and psychological distress in palliative care</i></u>	<u>228</u>
<u><i>Addressing limitations of the research</i></u>	<u>230</u>
<u>Final conclusions</u>	<u>233</u>
<u>Appendix A: Psychological Measures</u>	<u>235</u>
<u>Appendix B: Interview schedule for studies 1 and 2</u>	<u>241</u>
<u>Appendix C: Identification of predicates</u>	<u>244</u>
<u>Appendix D: Script for Guided Self-Help Intervention</u>	<u>247</u>
<u>Appendix E: Information booklet to accompany guided self-help intervention</u>	<u>259</u>
<u>Appendix F: Pro forma for telephone follow up sessions</u>	<u>263</u>
<u>Appendix G: Strategies and materials used to facilitate recruitment to randomized controlled study</u>	<u>268</u>
<u>Appendix H: Screening questions for RCT of guided self-help intervention</u>	<u>272</u>
<u>Appendix I: Checklist used to assess nurses' competence in guided self-help</u>	<u>273</u>
<u>Appendix J: Training programme presentation</u>	<u>274</u>
<u>Appendix K: Face-valid questions assessing nurses' behaviour, competence and confidence</u>	<u>286</u>
<u>REFERENCES</u>	<u>288</u>

TABLES & FIGURES

Table 1.1. Categories for coding of concerns (Adapted from De Faye et al., 2006)	
	42
Table 2.1. Categories for coding of concerns (Adapted from De Faye et al., 2006)	
	96
Table 2.2. Psychological distress, rumination, and concerns across groups (SD in parentheses)	100
Table 2.3. Correlations between psychological distress, concerns and rumination	102
Table 2.4. Constituents of the four domains of the WHOQOL-BREF (Adapted from Skevington et al., 2004)	106
Table 2.5. Quality of life and coping strategies across groups (SD in parentheses)	107
Table 2.6. Correlations between coping strategies, quality of life, psychological distress and rumination.	110
Table 3.1. Means for measures across groups (SD in parentheses)	127
Table 3.2. Correlations between abstractness, rumination, and symptoms.	128
Table 3.3. Examples of linguistic categories	132
Table 4.1. Inclusion and exclusion criteria for case series	144
Table 4.2. Means for psychological distress and quality of life measures pre and post training (SD in parentheses)	146
Table 4.3. Participant 1's quality of life before and after training	149
Table 4.4. Participant 2's quality of life before training	150
Table 4.5. Participant 3's quality of life before training	151
Table 4.6. Participant 4's quality of life before and after training	152
Table 4.7. Participant 5's quality of life before and after training	154

Table 4.8. Participant 6's quality of life before and after training	155
Table 5.1. Inclusion and exclusion criteria for the RCT.	167
Table 5.2. Characteristics of participants randomized to treatment and waiting-list control conditions	170
Table 5.3. Means [and 95% Confidence Intervals] for psychological distress and quality of life measures in treatment and control conditions at Time 1 and Time 2 (SD in parentheses)	175
Table 5.4. Means [and 95% Confidence Intervals] for abstractness measures in treatment and control conditions at Time 1 and Time 2 (SD in parentheses)	181
Table 6.1. Means [and 95% Confidence Intervals] for personal distress of patients receiving care from trained and waiting-list control teams pre- and post-training (SD in parentheses)	203
Table 6.2. Proportion of cases where self-reported behaviour is used and confidence measures in trained and waiting-list control teams at each assessment (SD in parentheses)	205
Table 6.3. Means [and 95% Confidence Intervals] for baseline characteristics and psychological distress in training and control conditions pre- and post-training used for matched sample parametric analysis (SD in parentheses)	210
Table 6.4. Median psychological distress in training and control conditions pre- and post-training used for non-parametric analysis	212
Table 7.1. Summary of hypotheses and findings	218
Figure 1.1. Recommended Model of Professional Psychological Assessment and Support (NICE, 2004a, p78)	21

Figure 2.1. Categorisation of coping strategies (Adapted from De Faye et al., 2006, p. 242)

93

Figure 4.1. Participants' anxious symptoms at each assesment 147

Figure 4.2. Participants' depressive symptoms at each assessment 148

Figure 5.1. Participant flow chart following Consolidated Standards of Reporting Trials guidelines. 168