

Exploring the psychological impact of life-limiting illness using the Attitude to Health Change scales: A qualitative focus group study in a hospice palliative care setting.

Abstract

Objective: Practitioners are often reluctant to engage in conversations that acknowledge patient's health concerns. This can affect patient and family carer psychological well-being. The Attitude to Health Change scales, adapted from the validated Adult Attitude to Grief scale, may have potential to address the psychological impact of illness and facilitate conversations in palliative care.

To explore how health and social care professionals experience using the Attitude to Health Change Scales within hospice settings.

Methods: Qualitative focus groups with practitioners currently using the Attitude to Health Change scales in three UK hospices. Two researchers conducted the interviews, developed the thematic framework and independently coded the transcripts using a framework analysis approach.

Results: Three focus groups (n=21 practitioners). The scale was used to assess and reassess levels of vulnerability and resilience to identify the need for support and to facilitate structured in-depth conversations. Factors that influenced scale implementation included: practitioner personal comfort and training; patient and family carer willingness to engage with the scales and having a practitioner 'champion' within the organisation.

Conclusion: This exploratory work has identified the potential value of the scales for assessment and to facilitate conversations. Further research needs to incorporate the views of patients and family carers.

Key words: Palliative Care; Qualitative Research; Psychosocial Support Systems; Resilience, Psychological

1. Introduction

Psychological distress is common in patients and their family carers receiving palliative care or those living with advanced progressive disease (Boakye et al., 2019; Hofmann et al., 2017; Rodin et al., 2018). There are higher rates of distress seen in patients with increased symptom burden (Fitzgerald et al., 2015). At its most severe, distress may lead to disabling symptoms such as depression and anxiety, with high prevalence of major depression (14.3%), adjustment disorders (15.4%) and anxiety disorders (9.8%) in palliative care settings (Mitchell et al., 2011).

The psychological needs of patients and family carers may range from information giving and compassionate communication to more formal or specialist psychological interventions such as counselling (Kozlov, Niknejad, & Reid, 2018). In the UK, national guidance recommends four levels of psychological support (Figure 1), with those with more complex needs requiring support from counsellors, psychologists, psychotherapists, mental health nurses or psychiatrists (National Institute for Health and Care Excellence, 2004). This is seen as best practice both nationally (National Institute for Health and Care Excellence, 2017) and internationally (O'Malley, Blakley, Ramos, Torrence, & Sager, 2020; PAYNE & JUNGER, 2011).

<Insert Figure 1 around here>

Health and social care practitioners can find it challenging to assess psychological symptoms (Thekkumpurath, Venkateswaran, Kumar, & Bennett, 2008). This means patients and family carers may not receive the type of support they require (Oechsle, 2019; Wang, Molassiotis, Chung, & Tan, 2018). Psychological symptoms can be underestimated as they are assumed to be expected in this population (O'Malley et al., 2020). Symptoms such as fatigue may be mistaken for side effects of underlying disease or treatment (Boakye et al., 2019) and it can be unclear whose role it is to provide psychological care (Kozlov et al., 2018). Practitioners also often avoid or are reluctant to engage in conversations that acknowledge uncertainty because of lack of confidence and fear of taking away hope (Almack, Cox, Moghaddam, Pollock, & Seymour, 2012). A key challenge for best practice in end of life care is ensuring those patients who wish to talk about their illness and its impact have the opportunity to do so (Momen, Hadfield, Kuhn, Smith, & Barclay, 2012). Poor communication is often a source of complaints in health care including in palliative care (Department of Health and Social Care, 2013).

This clinical need may be addressed by practitioners using a tool that is able to assess palliative care patient and family carer's psychological needs and facilitate challenging conversations. The Attitude to Health Change scales (see supplementary data) may have the potential to identify whether palliative care patients and their family carers require specialist psychological support. It may facilitate in depth conversations by providing practitioners with a structure to explore patient and family carer psychological concerns. The scales are distinct in that they are not 'symptom' based but explore the underlying dynamics which shape a person's capacity to deal with the impact of life limiting illness. The scales, a patient and a

carer version, have been adapted from the validated Adult Attitude to Grief scale (Sim, Machin, & Bartlam, 2014) and the 9-item scale covers three categories; controlling functioning, overwhelming emotion and resilient coping (Table1).

Please insert Table 1 here

Vulnerability is calculated by combining the overwhelmed and controlled scores with the reversed order of the resilient scores (Sim et al., 2014). The scales underlying concepts are based on the Range of Response to Loss theoretical model (Machin, 2014). This model describes the interaction between unconscious, reflexive reactions and conscious coping responses to loss and change.

The Attitude to Health Change scales have been implemented in a small number of UK hospices already using the precursor Adult Attitude to Grief Scale. The overall aim of this study was to explore how health and social care practitioners experience using the Attitude to Health Change scales within hospice settings with palliative care patients and their family carers. The importance of exploring their views and experiences of using the scales to explore acceptability and establish face validity was recognised. This paper is focused on the qualitative analysis of the focus groups and the consequent process of modifying the scale's wording will be reported separately. This is part of a wider study of face validity preceding formal scale psychometric validation.

2. Methods

2.1 Study Design

Qualitative focus group interviews were used as the dynamic interaction between participants should elicit a wider variety of practitioner views than individual interviews (Barbour, 2007). An interpretative hermeneutic approach was followed (McCaffrey, Raffin-Bouchal, & Moules, 2012) and the study was informed by the Range of Response to Loss theoretical model (Machin, 2014). The COREQ checklist was used to guide reporting of the study (Tong, Sainsbury, & Craig, 2007).

2.2 Population and sampling

Few hospices currently have experience of using the scales. Participants were sampled from three of these UK hospices currently using the scales. The protocols for use with the Adult Attitude to Grief scale were used as the basis for implementing the Attitude to Health Change scales. Participants were eligible if they were involved in using the Attitude to Health Change scales in practice and/or who worked or volunteered within the hospice in a role which primarily or partly encompassed psychosocial support of patients and their family carers, and where they had experienced others using and discussing the Attitude to Health Change scales. Two of the participants had not yet had the opportunity to complete the Attitude to Health Change scale with a patient or family carer but one of these practitioners had experience of using in the Adult Attitude to Grief Scale in their practice.

2.3 Recruitment

A key contact in each hospice circulated the study information to practitioners and volunteers who were eligible for the study. Those who were interested in taking part in the focus group responded to the research team by telephone, email or via a reply slip.

2.4 Data collection

Focus groups were carried out on hospice premises. LD led the focus groups as LM was known to the participants. LD, a nurse researcher, had no experience of using the scales and was not known to the participants. Field notes were taken by LM during and immediately after each interview. All focus groups were audio-recorded and transcribed verbatim (Barbour, 2007). The topic guide covered: initial reactions to the scales, how they were being used, positive and unsatisfactory experiences, how they felt patients and carers responded to the scales and their views on the wording of the scales (see supplementary data). Participants completed a short demographic questionnaire at the start of the focus group. Data collection ended when all eligible participants who wished to participate in the study had taken part and similar issues were being identified across the three hospices (Guest, Namey, & McKenna, 2017).

2.5 Data analysis

Framework analysis was used to facilitate within and across focus group analysis. (Gale, Heath, Cameron, Rashid, & Redwood, 2013) A coding framework was inductively constructed by LD and LM by examining the initial transcript. The framework was then applied by LD and LM to the subsequent transcripts. NVivo¹² was used to iteratively develop the framework and manage coding of transcripts. Charts were created to compare and contrast within and across the focus groups. Any discrepancies were discussed with input as required from CW until consensus was achieved. Participants did not provide feedback on the findings.

2.6 Ethical considerations

Research Ethics Committee approval was obtained from Lancaster University's Faculty of Health and Medicine Research Ethics Committee (Ref, FHMREC18009) on the 5th October 2018. Organisational approval was also obtained from each of the hospices taking part. All participants provided written informed consent prior to data collection.

3. Results

Data collection occurred between February 2019 and March 2019 with 21 practitioners taking part in three focus group interviews across the hospice sites. (table 2) The mean focus group length was 73 minutes (range 60–90 minutes). The hospices varied in size with the number of inpatient beds ranging from 10 to 26 and the number of hospice referrals ranging from 1023 to 3000 per year.

Please insert table 2 here

Initially, an outline is given of the use of the Attitude to Health Change scales in clinical practice. How the scales were being used to assess, as outcome measures, and to facilitate conversations is then explored. How organisational, practitioner and patient and carer related issues influenced how the scales were implemented and used in practice will also be examined. A selection of participant quotes will be used to illustrate the findings both in the sections below and in table 3.

The scales were being used by paid and volunteer practitioners responsible for providing specialist psychosocial support. Volunteers had recognised counselling qualifications and/or had undertaken appropriate in-house training. In the hospices, specialist psychosocial practitioners provided support at particularly challenging or distressing times throughout the patient's journey and family carer support would continue post bereavement if there was a need for on-going support. In site one, it was also being used by practitioners whose primary role was not to provide specialist psychosocial support. All sites had a practitioner champion in place promoting and supporting the implementation of the scales into clinical practice. The scales were being used variably and flexibly to assess levels of vulnerability and resilience as indications of the need, or not, for on-going psychological support, as outcome measures and/or to facilitate structured in-depth conversations.

3.1 Using the Attitude to Health Change scales as assessment tools

The scales were being used to assess patients and carers on initial entry into the service responsible for providing specialist psychosocial support. The information would then be used to determine whether ongoing psychological support was required and the type of support that should be offered.

'...we ask them to complete the form and then give it to us and then we then look at that before we start our assessment, and so we use it partly because it does inform what we're up to but it also gives us some guidelines actually about what kind of service we might need to offer, how are people doing, do they need a service actually or are they doing ok?' (P2S2)

In site one, they were also being used by a wider multi-disciplinary team as a psychological screening tool. This information would be used by the team to decide whether a referral to specialist psychosocial services was required. Interpreting the scores in conjunction with the qualitative information obtained during the assessment process, was seen as important for ensuring an appropriate plan of care was put in place.

'.....I think it (qualitative responses to the scale) helps you really unpack what does this (scores) mean, what does it look like, should I be alerted, should I be concerned, or actually is there stuff that explains why it would be natural for someone to answer some of these questions as they have, but it is laborious.' (P4S1)

3.2 Using the Attitude to Health Change scales as outcome measures

The scales were used to reassess patient and family carer's levels of vulnerability and resilience. The ability to use the scales in this way was dependent on the stability of the patient's physical condition.

'...and equally the family member that's exactly it, all of a sudden you see this massive shift of scores going up intensely which is what I expect, the person is dying....' (P5S1)

This lack of stability meant using the scales as an outcome measure could be challenging for practitioners. Skilled communication and clinical assessment were required by practitioners when using the scales. Practitioners recognised that an increase in the vulnerability score may not have indicated that support had been ineffective but rather that the responses to the scales were being made at the time of significant changes or deterioration in the patient's health.

'...and that's the only I think criticism of it, is that I'm not sure we could call this an outcome measure in its true form because actually before and after..... don't show clinical effectiveness because actually it looks like we're bombing, you know but that's ok, there's a story behind it which again is the beauty of the qualitative stuff that comes round,' (P5S1)

3.3 Using the Attitude to Health Change scales as a conversational guide

Across the three sites, the scales were also being used qualitatively as a conversational guide. The scales were being used as a framework to facilitate conversations with patients and their family carers. In sites one and three, non-level three or four practitioners were also using it in this way.

'...it's useful for me as coming from a different background (level two practitioner) to just have a list of questions that start a conversation and then we can have answers to, whether or not it's always appropriate to use it you have to decide there or then,' (P10S1)

It could provide a structure to encourage patients and family carers to talk about things they may not have previously discussed or openly acknowledged. Practitioners felt this could be an innately therapeutic process for some patients and family carers. In these instances, the scales moved from a more 'functional' quantitative assessment tool to a more qualitative 'clinical' therapeutic conversational guide.

'...other people will talk about each question and really want to go into it, so it varies when it's a clinical tool and when it's a sort of a functional, practical tool..' (P1S3)

How the scales were being used as a conversational guide was influenced by the practitioner's professional background and role. Some practitioners would use the scales in their formal therapy work and these types of conversations were the vehicle for more focused interventions aimed at addressing vulnerability and seeking to enhance resilience.

‘.I do body orientated work, so naming things and language coming from a felt sense and encouraging that process is like really, I really value that way of working, so that’s why the words and taking time with it (Attitude to Health Change scale) and almost using it to question to see what it brings with the body and what emotions underneath each word, that’s why I said that way, not as an assessment’. (P2S1)

3.4 Organisational readiness to engage with the Attitude to Health Change scales

Use of the scales was largely confined to those hospice teams responsible for providing specialist psychosocial support as it was seen to be pertinent to their practice role. In site one, the scales were being introduced alongside another psychological scale called CORE (Barkham et al., 2013) as the service felt CORE did not address loss and grief.

‘...we find it very helpful (CORE), and we’ve been using it now for four plus years, but it was missing the loss and the grief aspect of the business, and so actually it was like ok well we want to see the full picture, what is out there, and hence the AHC [Attitude to Health Change scale] and the AAG [Adult Attitude to Grief scale] in many ways.’ (P5S1)

Alternative psychological assessment scales were reported as being used by the wider multi-professional hospice team in site two. The training undertaken by participants had been in the protocols for using with the Adult Attitude to Grief scale. Information was cascaded down to team members usually by the practitioner who had introduced the scales into the organisation and attended the training by the scale developer. The need for specific training in use of the Attitude to Health Change scales was identified with a focus on the scale’s purpose, its underlying concepts, how to introduce it, how to interpret the scoring and managing carer transition from pre bereavement to post bereavement support.

‘...but I found it really difficult to introduce and I kept taking the form and each time and I really tried to bring it into the session but it took I think three sessions before we were able to touch base with it...’ (P4S2)

In addition to formal clinical supervision, the need for support from more experienced colleagues was identified as crucial to the effective use of the scales.

3.5 Practitioner readiness to engage with the Attitude to Health Change scales

Across the focus groups, practitioners had variable experience of using the scales. How it was used was influenced by the individual practitioner’s clinical role and the requirements of the organisation.

‘...would only be using this one if you like if the focus of the referral was psychological support rather than social or practical or whatever else which as a social worker I also work in that way.’ (P5S3)

Resistance and readiness appeared to be related to practitioner confidence and misunderstandings about the purpose of the scales and how to use them. Some practitioners

were worried that it would interfere with their therapeutic patient centred work. For some, this concern appeared to reduce with increased familiarity using the scale.

'..initially I felt it would interrupt that work and it would maybe be bringing in things that were not relevant at that time, but actually since then having used it, I've found it to be a very helpful tool in perhaps highlighting things, perhaps bringing things in that had been either not mentioned or not brought into the sessions, or even to an extent denied by the client, and it allowed those things to be spoken about. So I find it very helpful now as a tool to help move things on with clients.' (P3S3)

A minority questioned the appropriateness of using the scales as it requires patients and carers to confront difficult issues. The practitioner's clinical judgement of the patients or family carer's willingness to engage with the scales, influenced how and whether it was used.

3.6 Patient and family carer readiness to engage with the Attitude to Health Change scales

Practitioners reported variable levels of patient and family carer readiness to engage with the scale. Practitioners in all sites spoke about patient and carer willingness to engage with the scale from the initial meeting or invitation to use it. For some patients and family carers it helped to confirm how they were feeling which provided reassurance.

'.. I seldom have a patient, well I've never had somebody refuse to do it. Generally when you explain it to them, how it's used, what the benefits are, the insight, it's about helping me to understand what your experience is is usually how I present it in simplest terms, and 99.9% of the time they're happy to go along with that and we sit together and go through it together, that's generally how I use it.' (P5S2)

The importance of explaining the purpose of the scale to patients and carers to increase acceptance was highlighted. Some patients and carers could be resistant to engaging with the scale as they viewed it as surveillance or a test or an extra questionnaire to complete and there could be confusion about the meaning of certain items in the scale.

'...but what it represents for lots of people and negative experiences of feeling you know kind of that they're being yeah assessed or that they're under surveillance or and I think that's a real pressure for some people and it's anxiety provoking.' (P8S1)

Practitioners reported that some patients and carers could find the questions confronting or intrusive, while others just felt too emotionally overwhelmed by their situation to engage with the scales. The challenge for practitioners of managing patient and carer denial and avoidance while using the scales in clinical practice was raised in all three sites. Figure 2 provides a visual representation of the main themes and subthemes identified and how they are interlinked.

Please insert Figure 2 here

Please insert Table 3 here

4. Discussion

4.1 Discussion

In this study, psychosocial practitioners reported that the Attitude to Health Change scales can have value in their ability to assess and reassess levels of vulnerability and resilience, help identify an appropriate plan of care and facilitate in depth therapeutic conversations. However, a number of wider contextual issues influenced how it was used and implemented within the three hospice sites.

This study has shown that reassessing levels of vulnerability and resilience and measuring the effectiveness of a therapeutic intervention in the palliative care population can be challenging. Patient and family carer concerns and symptoms may worsen as the patient's condition deteriorates (Murtagh et al., 2019). Scale scores may increase but this may not indicate that a clinical intervention has been ineffective. In order for scales, such as the Attitude to Health Change scales to be implemented successfully into clinical practice, practitioners require training on their use including how to interpret the scoring in light of the patient's clinical condition (Antunes, Harding, & Higginson, 2014). This study has demonstrated that the scales may assist practitioners when assessing psychological needs. They do not, however, replace the role of skilled communication and clinical evaluation (Kelly, McClement, & Chochinov, 2006).

This study has illustrated how patient denial and avoidance can make it challenging for practitioners to introduce a tool such as the Attitude to Health Change scales and how this issue can occur even in an 'open awareness' setting such as a hospice (Copp & Field, 2002). There are differing reports of how open patients are to having conversations that may involve discussions about the end of life (Almack et al., 2012; Piers et al., 2013). Palliative care patients can find it difficult to raise how they are feeling about their illness (Momen et al., 2012) and expect practitioners who are looking after them to initiate the conversation (Almack et al., 2012). In this study, practitioners found using a conversational guide a positive as well as a challenging experience and similar experiences were reported in a recent advance care planning study (Zwakman et al., 2019). As indicated in our findings, the importance of training, learning by experience and having the opportunity to take part in reflective discussions was seen to increase practitioner self-confidence (Zwakman et al., 2019). The importance of being attuned to palliative care patients and family carers levels of understanding and readiness (Etkind, Bristowe, Bailey, Selman, & Murtagh, 2017) especially when using a conversational guide (Zwakman et al., 2019), such as the Attitude to Health Change scales, needs to be recognised.

The scales were largely being used by psychosocial care teams. Outside this specialist field, practitioners can find having conversations with patients and family carers around changes in their health and end of life care challenging (Pfeil, Laryionava, Reiter-Theil, Hiddemann, & Winkler, 2015). This can be an issue even for health care professionals whose role is to provide specialist palliative care support and advice (Pontin & Jordan, 2011). Specialist palliative care

is provided by professionals specifically trained in palliative care who work full time in this area (Bausewein & Higginson, 2012). According to UK guidance, their role is to provide level two psychological support which involves screening for psychological distress and eliciting concerns and feelings through effective communication skills which may prevent the need for referral to specialist psychological services (see figure 1) (National Institute for Health and Care Excellence, 2004). This study has shown that there is the potential for level two practitioners to use the Attitude to Health Change scales in their practice to screen for psychological distress and to facilitate conversations. The scales may also have utility for those practitioners who work outside specialist palliative care.

Further research is required before the scales are implemented more widely and it is important to adopt a cautious approach when adapting interventions to other settings or populations as illustrated by the Liverpool Care Pathway in the UK (Department of Health and Social Care, 2013). A number of recommendations from this preliminary work have been identified and include: the need for organisational support for use of the scales, including a commitment to training; specific guidelines on how to use the scales, while based on the Adult Attitude to Grief protocols, need to be designed to reflect the clinical uncertainty that is a characteristic of this patient population and formalised training in use of the scales and ongoing support, to increase practitioner comfort and readiness to engage with the scale.

4.2 Strength and Limitations

The study included the perspectives of a variety of specialist psychosocial practitioners across a number of hospices. The limitations were it did not include the views and experiences of patients and family carers and participants already had experience of using the Adult Attitude to Grief Scale.

4.3 Conclusion

This exploratory work has identified the potential value of the Attitude to Health Change scales for psychological assessment and to facilitate challenging conversations with palliative care patients and their family carers. Formal psychometric scale validation work needs to be undertaken as well as research that explores patient and family carer's experiences of taking part in an Attitude to Health Change scale facilitated conversation.

References

- Almack, K., Cox, K., Moghaddam, N., Pollock, K., & Seymour, J. (2012). After you: conversations between patients and healthcare professionals in planning for end of life care. *BMC Palliative Care*, *11*(1), 15. doi:10.1186/1472-684X-11-15
- Antunes, B., Harding, R., & Higginson, I. J. (2014). Implementing patient-reported outcome measures in palliative care clinical practice: a systematic review of facilitators and barriers. *Palliat Med*, *28*(2), 158-175. doi:10.1177/0269216313491619
- Barbour, R. (2007). *Doing focus groups*: SAGE Publications.
- Barkham, M., Bewick, B., Mullin, T., Gilbody, S., Connell, J., Cahill, J., . . . Evans, C. (2013). The CORE-10: A short measure of psychological distress for routine use in the psychological therapies. *Counselling and Psychotherapy Research*, *13*(1), 3-13. doi:10.1080/14733145.2012.729069

- Bausewein, C., & Higginson, I. J. (2012). Challenges in defining 'palliative care' for the purposes of clinical trials. *Curr Opin Support Palliat Care*, 6(4), 471-482. doi:10.1097/SPC.0b013e32835998f5
- Boakye, E. A., Osazuwa-Peters, N., Mohammed, K. A., Challapalli, S., Buchanan, P., Burroughs, T. E., & Varvares, M. A. (2019). Prevalence and factors associated with diagnosed depression among hospitalized cancer patients with metastatic disease. *Social Psychiatry and Psychiatric Epidemiology*, 1-9.
- Copp, G., & Field, D. (2002). Open awareness and dying: The use of denial and acceptance as coping strategies by hospice patients. *NT Research*, 7(2), 118-127. doi:10.1177/136140960200700206
- Department of Health and Social Care. (2013). *More Care, Less Pathway. A Review of the Liverpool Care Pathway.*
- Etkind, S. N., Bristowe, K., Bailey, K., Selman, L. E., & Murtagh, F. E. (2017). How does uncertainty shape patient experience in advanced illness? A secondary analysis of qualitative data. *Palliat Med*, 31(2), 171-180. doi:10.1177/0269216316647610
- Fitzgerald, P., Lo, C., Li, M., Gagliese, L., Zimmermann, C., & Rodin, G. (2015). The relationship between depression and physical symptom burden in advanced cancer. *BMJ Supportive & Palliative Care*, 5(4), 381-388.
- Gale, N. K., Heath, G., Cameron, E., Rashid, S., & Redwood, S. (2013). Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol*, 13(1), 117. doi:10.1186/1471-2288-13-117
- Greene, R. R. (2002). Holocaust survivors: A study in resilience. *Journal of Gerontological Social Work*, 37(1), 3-18.
- Guest, G., Namey, E., & McKenna, K. (2017). How many focus groups are enough? Building an evidence base for nonprobability sample sizes. *Field methods*, 29(1), 3-22.
- Hofmann, S., Hess, S., Klein, C., Lindena, G., Radbruch, L., & Ostgathe, C. (2017). Patients in palliative care—Development of a predictive model for anxiety using routine data. *PLoS One*, 12(8).
- Kelly, B., McClement, S., & Chochinov, H. M. (2006). Measurement of psychological distress in palliative care. *Palliat Med*, 20(8), 779-789. doi:10.1177/0269216306072347
- Kozlov, E., Niknejad, B., & Reid, M. (2018). Palliative care gaps in providing psychological treatment: a review of the current state of research in multidisciplinary palliative care. *American Journal of Hospice and Palliative Medicine*, 35(3), 505-510.
- Machin, L. (2014). *Working with loss and grief: a theoretical and practical approach*: Sage.
- McCaffrey, G., Raffin-Bouchal, S., & Moules, N. J. (2012). Hermeneutics as research approach: A reappraisal. *International Journal of Qualitative Methods*, 11(3), 214-229.
- Mikulincer, M., Florian, V. (1998). The Relationship Between Adult Attachment Styles and Emotional and Cognitive Reactions to Stressful Events. In J. A. Simpson, Rholes, W. S (Ed.), *Attachment Theory and Close Relationships* (pp. 143-165). New York: Guildford Press.
- Momen, N., Hadfield, P., Kuhn, I., Smith, E., & Barclay, S. (2012). Discussing an uncertain future: end-of-life care conversations in chronic obstructive pulmonary disease. A systematic literature review and narrative synthesis. *Thorax*, 67(9), 777-780. doi:10.1136/thoraxjnl-2012-201835
- Murtagh, F. E., Ramsenthaler, C., Firth, A., Groeneveld, E. I., Lovell, N., Simon, S. T., . . . Bausewein, C. (2019). A brief, patient- and proxy-reported outcome measure in advanced illness: Validity, reliability and responsiveness of the Integrated Palliative care Outcome Scale (IPOS). *Palliat Med*, 33(8), 1045-1057. doi:10.1177/0269216319854264
- National Institute for Health and Care Excellence. (2004). *Improving supportive and palliative care for adults with cancer: The manual* Retrieved from
- National Institute for Health and Care Excellence. (2017). *End of life care for adults*. Retrieved from
- O'Malley, K., Blakley, L., Ramos, K., Torrence, N., & Sager, Z. (2020). Mental healthcare and palliative care: barriers. *BMJ Supportive & Palliative Care*.

- Oechsle, K. (2019). Current advances in palliative & hospice care: Problems and needs of relatives and family caregivers during palliative and hospice care—An overview of current literature. *Medical Sciences*, 7(3), 43.
- PAYNE, S., & JUNGER, S. (2011). Guidance on postgraduate education for psychologists involved in palliative care. *European Journal of Palliative Care*, 18(5), 238-252.
- Pfeil, T. A., Laryionava, K., Reiter-Theil, S., Hiddemann, W., & Winkler, E. C. (2015). What Keeps Oncologists From Addressing Palliative Care Early on With Incurable Cancer Patients? An Active Stance Seems Key. *Oncologist*, 20(1), 56-61. doi:10.1634/theoncologist.2014-0031
- Piers, R. D., van Eechoud, I. J., Van Camp, S., Grypdonck, M., Deveugele, M., Verbeke, N. C., & Van Den Noortgate, N. J. (2013). Advance Care Planning in terminally ill and frail older persons. *Patient Educ Couns*, 90(3), 323-329. doi:<https://doi.org/10.1016/j.pec.2011.07.008>
- Pontin, D., & Jordan, N. (2011). Issues in prognostication for hospital specialist palliative care doctors and nurses: A qualitative inquiry. *Palliat Med*, 27(2), 165-171. doi:10.1177/0269216311432898
- Rodin, G., Lo, C., Rydall, A., Shnall, J., Malfitano, C., Chiu, A., . . . Nissim, R. (2018). Managing Cancer and Living Meaningfully (CALM): A randomized controlled trial of a psychological intervention for patients with advanced cancer. *Journal of Clinical Oncology*, 36(23), 2422.
- Seligman, M. E. (1998). Building human strength: Psychology's forgotten mission.
- Sim, J., Machin, L., & Bartlam, B. (2014). Identifying vulnerability in grief: psychometric properties of the Adult Attitude to Grief Scale. *An International Journal of Quality of Life Aspects of Treatment, Care and Rehabilitation - Official Journal of the International Society of Quality of Life Research*, 23(4), 1211-1220. doi:10.1007/s11136-013-0551-1
- Thekkumpurath, P., Venkateswaran, C., Kumar, M., & Bennett, M. I. (2008). Screening for Psychological Distress in Palliative Care: A Systematic Review. *J Pain Symptom Manage*, 36(5), 520-528. doi:10.1016/j.jpainsymman.2007.11.010
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357. doi:10.1093/intqhc/mzm042
- Wang, T., Molassiotis, A., Chung, B. P. M., & Tan, J.-Y. (2018). Unmet care needs of advanced cancer patients and their informal caregivers: a systematic review. *BMC Palliative Care*, 17(1), 96.
- Zwakman, M., Pollock, K., Bulli, F., Caswell, G., Červ, B., van Delden, J. J. M., . . . On behalf of the, A. c. (2019). Trained facilitators' experiences with structured advance care planning conversations in oncology: an international focus group study within the ACTION trial. *BMC Cancer*, 19(1), 1026. doi:10.1186/s12885-019-6170-7

Table 1: Definitions

Overwhelming distress reactions: These reactions are characterised by disturbingly intrusive thoughts, persistently painful emotions and a sense of life losing its meaning (Mikulincer, 1998).

Controlled reactions: These reactions are characterised by a belief in stoicism, avoidance of expression of distress and diverting attention away from what has been or is being lost (Mikulincer, 1998).

Resilient coping responses: These responses are characterised by an ability to face the feelings of loss, a sense of personal resourcefulness to cope with the consequences of loss, and a hopeful and positive sense of being able to accept the loss (Greene, 2002; Seligman, 1998).

Table 2: Summary of practitioner characteristics

		Site 1	Site 2	Site 3
Total number of participants		10	5	6
Role in hospice	Family support team manager	1	1	1
	Social worker/counsellor	2	0	0
	Social worker	1	0	0
	Counsellor	2	2	3
	Spiritual care lead	1	0	0
	Physiotherapist	1	0	0
	Specialist nurse	1	0	0
	Psychologist	1	0	0
	Volunteer	0	2	2
Practitioner hours of work per week (range)		21 - 37.5	03 - 30	5 -32.5
Length of experience in hospice work or allied field pertinent to palliative or bereavement care	>5 years	7	2	3
	3-5 years	2	1	2
	1-2 years	0	2	1
	<1 year	1	0	0

How many months individual practitioners have been using the scales (range)	0-1 month	3	0	0
	2-6 months	7	2	0
	7-12 months	0	0	0
	13-24 months	0	2	2
	25 + months	0	1	4
Approximate number of patients and carers individual practitioners have used the Attitude to Health Change scales with	Patients			
	0-1	5	2	1
	2-6	4	0	2
	7-12	1	2	1
	13-24	0	0	0
	25+	0	0	2
	Missing data	0	1	0
	Carers			
	0-1	5	2	0
	2-6	4	0	2
	7-12	1	2	0
	13-24	0	0	1
	25+	0	0	3
	Missing data	0	1	0

Table 3: Illustrative quotes

Themes	Quotes
<p>Using the Attitude to Health Change scales as an assessment tool</p>	<p><i>'....you can kind of go through it and see where they're falling into, whether they're controlling the situation or what they're doing or how they're responding so then it kind of gives you a bit more insight into their personal response to their illness, sometimes'. (P10S1)</i></p> <p><i>'So I'm making a judgement about when and sometimes I'm hearing that the patient's already talking to some of these things, so it [Attitude to Health Change scale] can be quite a good way of combining it..' (P4S3)</i></p>
<p>Using the Attitude to Health Change scales as an outcome measurement</p>	<p><i>'...with the AAG [Adult Attitude to Grief Scale used in bereavement] that's quite you know yes we have six sessions then we can do another one, but with patients it's very different because you haven't got that time, you don't know how long you're going to be seeing them, you don't know, so it is quite difficult to have a more rigid procedure to them I think.' (P3S2)</i></p>
<p>Using the Attitude to Health Change scales as a conversational guide</p>	<p><i>'I think it just asks some very specific questions about all number of things, so that's quite a useful framework to have. And it starts a conversation about how they're managing if you want to use it in that way.(P10S1)</i></p> <p><i>'...it's difficult for them to for some people to express what they're feeling, and this is a good tool in that it actually gets people talking about things' (P6S3)</i></p>

<p>Organisational readiness to engage with the Attitude for Health Change scales</p>	<p><i>'In context of a counselling kind of assessment, it felt very appropriate.'</i> (P5S3)</p> <p>Examples of training requirements</p> <p><i>'I think as a service we haven't really had a follow up about that (interpretation of scores), the complexities of how do we make sense of or interpret it in some ways that are useful ways, I think we're all kind of like trying to feel our way through that and make sense of it.'</i> (P8S1)</p> <p><i>'...I guess I was slightly resistant because at the beginning I couldn't actually see how it was going to help the work we were doing, I think I'd sort of got in mind initially it was more of a research tool, it was more for the use here of keeping statistics..'</i> (P3S3)</p>
<p>Practitioner readiness to engage with the Attitude to Health Change scales</p>	<p><i>'.... the first two sessions I said we could talk about this, but it just didn't feel right, so I did play it by ear until the third session where I felt that we were able to really she was ready to sort of start answering some of these questions, but it was a very gentle process.'</i> (P4S2)</p>
<p>Patient and carer readiness to engage with the Attitude to Health Change scales</p>	<p><i>'I mean some people which I really like of course is they'll say oh that just puts down in black and white exactly what I've been feeling, and there's something about that that is reassuring for some, sometimes shocking for others, it's like oh God there it is in black and white as opposed to oh someone gets me...'</i>(P1S3)</p> <p><i>'...I did do the attitude to change with the patient, the person who's now died, but a lot of their responses at the time, they'd answer something but then they'd just report they were blank, they couldn't give any kind of qualitative, they couldn't really kind of let me know why it was that they'd agreed with that item or</i></p>

	<p><i>answered in the way that they had, which again it felt it was yeah they were associating or they were just disconnected from it, so it didn't feel like it had as much utility,' (P8S1)</i></p> <p><i>'...there was a client who it presented, in the first session, and I could see he was just overwhelmed by it and it didn't fit, so I said let's just leave it aside and let's just talk' (P2S1)</i></p>
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