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Attitudes of palliative care clinical staff toward prolonged grief disorder diagnosis and grief interventions

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Attitudes of palliative care clinical staff toward prolonged grief disorder diagnosis and grief interventions

Abstract

Copyright Cambridge University Press 2017 Objective:: The provision of psychological support to caregivers is an important part of the role of the clinical staff working in palliative care. Staff knowledge and attitudes may determine their openness to referring caregivers to a psychological intervention. We recently developed a self-help intervention for grief and psychological distress among caregivers and were interested in exploring the extent to which staff knowledge and attitudes might affect future implementation. The aims of our study were to: (1) examine the acceptability of self-help psychological intervention for caregivers among palliative care clinical staff; (2) examine potential attitudinal barriers toward prolonged grief disorder (PGD) as a diagnosis and interventions for grief; and (3) bolster staff confidence in skills and knowledge in identifying and managing caregiver psychological distress. Method:: An anonymous survey was distributed among clinical staff at two inpatient units and two community health services that assessed the acceptability of self-help interventions for caregivers, attitudes about PGD diagnosis and grief intervention, and staff confidence in skills and knowledge in assessing caregiver psychological distress. Results:: Overall, clinical staff were positively oriented toward self-help for caregivers and intervention for grief. They were also basically confident in their skills and knowledge. While it was positive PGD attitudes that were associated with acceptability of self-help for caregivers, it was both positive and negative PGD attitudes that were associated more specifically with a willingness to refer caregivers to such an intervention. Significance of results:: Our findings are useful in highlighting the issues to be considered in the implementation of a self-help intervention within the healthcare service. Clinical staff seemed positively oriented toward engaging with a psychological intervention for caregivers and likely to act as key allies in implementation.

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Attitudes of palliative care clinical staff toward Prolonged Grief Disorder diagnosis and grief interventions

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ABSTRACT

Objectives: The provision of psychological support to carers is an important part of the role amongst clinical staff working in palliative care. Staff knowledge and attitudes may determine their openness to referring carers to a psychological intervention. We recently developed a self-help intervention for grief and psychological distress among carers and were interested in exploring the extent that staff knowledge and attitudes might affect the future implementation. The aims of this study were to: 1) examine the acceptability of self-help psychological intervention for carers amongst palliative care clinical staff; 2) examine potential attitudinal barriers toward Prolonged Grief Disorder (PGD) as a diagnosis and interventions for grief; and 3) determine confidence in skills and knowledge in identifying and managing carer psychological distress.

Methods: An anonymous survey was distributed among clinical staff at two inpatient units and two community health services and assessed acceptability of self-help intervention for carers, attitudes toward PGD diagnosis and grief intervention, and confidence in skills and knowledge in assessing carer psychological distress.

Results: Clinical staff were overall positively oriented toward self-help for carers and intervention for grief. Staff were also largely confident in their skills and knowledge. While overall it was positive PGD attitudes that were associated with acceptability of self-help for carers, it was both positive and negative PGD attitudes that were associated more specifically with the willingness to refer carers to such an intervention.

Significance of Results: These findings are useful in highlighting the issues to be considered in the implementation of a self-help intervention within the health care service. Clinical staff seemed positively oriented toward engaging with psychological intervention for carers and are likely to act as key allies in implementation.

Key Words: palliative care, staff, attitudes, Prolonged Grief Disorder, carers

INTRODUCTION

Carers are part of the unit of care in palliative care (Hudson, 2003; World Health Organization, 2002), and hence the adequate provision of psychological support to carers is a priority for clinical staff working in palliative care. Clinical staff (e.g. nurses, doctors, social workers) usually work closely with carers leading up to the patients' death. They are therefore in a primary position to monitor carer psychological wellbeing and identify when a carer may require referral for specialist psychological support. However, identifying those who need or would benefit from psychological support can be a complex task. It requires an understanding of the range of stress and grief responses, and a working knowledge of various psychological disorders, all whilst managing patient care and multiple time and resource constraints.

The capacity and initiative of clinical staff to offer referral to a psychological intervention for carers underlies, in part, the successful implementation of a particular intervention within a health service. A study investigating palliative care nurse confidence in identifying and managing depression in palliative patients identified the need for further training in the signs and symptoms of depression, issues around discussing depression with patients and their family members, and difficulty differentiating depressive symptoms from grief (McCabe, Mellor, Davison, Hallford, & Goldhammer, 2012). Gaining an understanding of such areas in which clinical staff are more and less confident in their knowledge and skills in identifying and managing carer distress is likely to be important to the successful implementation of a psychological intervention. The acceptability of a particular approach is also likely to be key to them promoting the intervention (e.g., Lovell et al., 2008; Webster, Thompson, Norman, & Goodacre, 2017). Further, clinical staff engagement with interventions implemented prior to patient death and with an explicit intent to prevent Prolonged Grief Disorder (PGD) might be affected by attitudes toward both grief intervention and PGD as a diagnosis. How one

conceptualizes the appropriateness of another's grief has been shown to influence perceptions of the warranted level of social support and the willingness of people to be with the griever (Dyregrov, 2003; Thornton, Robertson, & Mlecko, 1991). Such research indicates that attitudes toward grief have the potential to influence behavioural intentions to help. An Australian survey of psychologists and counsellors opinions regarding PGD showed a strong level of clinical support for the recognition of PGD (73%), but many held concerns about the implications of pathologising grief (Ogden & Simmonds, 2014). This tension between support and concern was also reflected in an international survey of members of the public, in which 75% agreed that grief could be considered a mental disorder but they also held reservations about potential medicalization and stigma of grief (Breen, Penman, Prigerson, & Hewitt, 2015). It is possible that such concerns about pathologising and intervening with carer grief would influence the likelihood of clinical staff making referrals for psychological intervention.

We have recently developed a self-help intervention for grief and psychological distress in carers of patients in palliative care that is being tested in a feasibility trial (Davis, Deane, & Lyons, 2016). Consequently, the capacity of clinical staff to act as referrers to such an intervention and potential barriers to implementation were of particular interest. We therefore sought to: 1) examine the acceptability of self-help psychological intervention for carers amongst palliative care clinical staff who are likely to be primary referrers; 2) examine potential attitudinal barriers toward PGD as a diagnosis and interventions for grief; and 3) determine confidence in skills and knowledge in identifying and managing carer distress.

METHODS

Participants

Participants were recruited in 2016 from two inpatient palliative care units and two community health centres in the Illawarra-Shoalhaven region of NSW. Eligible clinical staff were health care workers (including nurses, registrars, and doctors) who provided direct care to patients and carers as part of the palliative care service at participating sites. Further eligibility criteria include being aged 18 years or over and having sufficient comprehension of English to be able to understand and complete the study documents.

[INSERT TABLE 1 HERE]

Procedure

Clinical staff were invited to complete a questionnaire broadly about the acceptability of psychological interventions for carers. Clinical staff did not need to have been involved in recruitment of carer participants to the feasibility trial of the self-help intervention. Line managers and the director of the palliative care service notified clinical staff of the questionnaire at routine staff meetings. They were informed of the purpose of the research and the voluntary nature of participation. The questionnaire was anonymous and paper copies were provided in meeting rooms alongside a participant information sheet. Completed questionnaires were collected by a researcher (ED) between two to three weeks after administration.

Measures

Demographics

Background information collected about participants included gender, age range, current occupation, duration of time spent in current role, and proportion of time spent working in community versus inpatient settings.

Acceptability of psychological intervention for carers.

A short paragraph describing guided self-help was provided after which respondents complete five items adapted from a modified version of the Treatment Evaluation Inventory (TEI; Kazdin, 1980; Kelley, Heffer, Gresham, & Elliott, 1989). The TEI has been used to compare perceptions of acceptability for different depression treatments including self-help (Hanson, Webb, Sheeran, & Turpin, 2016; Landreville & Guerette, 1998). Items assessed how acceptable clinical staff find guided self-help for psychological distress in carers (e.g. “I would be willing to suggest guided self-help to carers I see” and “I think guided self-help is an acceptable approach to help with a carer’s psychological distress”) and are rated on a 5-point scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). One item was reverse scored so that higher scores indicated higher ratings of acceptability. Cronbach alpha indicated that internal reliability of the measure in the current study was satisfactory ($\alpha = .79$).

Confidence in skills and knowledge. Seventeen items assessed clinical staff confidence in identifying and distinguishing between different presentations of abnormal psychological distress (i.e., anxiety, depression and grief) and managing such presentations in carers (e.g. “Knowing when it is time to raise concerns about a carer who might have abnormal psychological distress”). The items were modified from a 16-item questionnaire to assess nursing staff confidence in skills and knowledge for managing depression in palliative care patients (McCabe, Mellor, Davison, Hallford, & Goldhammer, 2012). Items were

reworded from being about the patient and depression to being about the carer and abnormal psychological distress. An additional item was added to emphasise the issue of normal distress in the context of grief, (“Being able to recognize that a carer might have normal levels of psychological distress”). Items were rated on a 4-point scale ranging from 1 (*not at all confident*) to 4 (*very confident*), with higher total scores indicating higher levels of confidence. The internal reliability of this scale has been reported as high ($\alpha=.94$) among Australian nurses (McCabe et al., 2012). Reliability in the current study using Cronbach alpha was also high ($\alpha = .95$).

Attitudes toward PGD as a diagnosis. A modified version of an 8-item questionnaire developed to measure attitudes of psychologists and counsellors towards classifying PGD as a psychiatric disorder (Ogden & Simmonds, 2014) was used. Items were reworded to be more understandable to staff without psychology backgrounds and changed from being about clients to being about carers. The item “I would use this diagnosis if it were available” was deleted as it was not considered applicable, leaving a total of 7 items. Proposed diagnostic criteria of PGD from the ICD-11 (Maercker et al., 2013) were provided and clinical staff rated their agreement to items (e.g. “I think that recognition of PGD may lead to the pathologisation of “normal” grief” and “Diagnosing PGD will increase carer likelihood of getting the best help possible”). Items were rated on a 5-point Likert-type scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Three items were reverse scored to calculate the total score, however Cronbach alpha indicated that internal reliability in the current study was poor ($\alpha=.56$). This is not uncommon when positive and negative items are included together (e.g., Salazar, 2015). To address this, the four positively worded items were separated from the three negatively worded items to create a PGD positive attitude subscale ($\alpha=.78$) and PGD negative attitude subscale ($\alpha=.75$) with improved reliability. Higher scores on PGD

positive attitude indicated more positive attitudes toward PGD as a diagnosis while higher scores on PGD negative attitude indicated more negative attitudes.

Attitudes toward grief intervention. Attitudes towards intervention for grief (pre- or post-loss) was measured by four purpose-designed items (e.g. “People should move through their grief without psychological intervention” and “It is best to leave people to move through grief in their own way and in their own time”). Clinical staff rated agreement with the items on a 5-point Likert-type scale ranging from 1 (*strongly disagree*) to 5 (*strongly agree*). Three items were reverse scored so that higher scores indicated more positive attitudes toward grief intervention. Cronbach alpha indicated that internal reliability in the current study was satisfactory ($\alpha = .75$)

Data analysis and management

Missing values of data were examined. If more than 80% of values were available within a scale, the mean of the available data for the individual participant was used (prorated scores). If less than 80% of values were available, the participant was removed from the sample. Based on these criteria, 5 cases were prorated and 1 case removed for a total sample size of 46.

Data were also examined for outliers and casewise diagnostics were used to detect any problematic cases, of which none were found. Normality plots and statistical tests of normality were inspected and showed that all variables approximated normality.

Mean scores and frequencies were used to summarise participants’ demographic details and scores on the outcome variables. Examination of potential differences in outcome variables based on demographics was examined in relation to age, years spent in current role and primary workplace (community or inpatient). Independent t-tests and ANOVA were used to analyse age and primary workplace and Pearson’s correlation for years spent in role.

Relationships between acceptability of self-help intervention, confidence in skills and knowledge, attitudes toward PGD diagnosis and attitudes toward grief intervention were explored using correlation analyses. All correlations used Pearson's correlation and were two-tailed since no specific directional hypotheses were predicted.

RESULTS

Sample

Across sites there was an estimated 127 clinical staff employed during the time the survey was administered (121 nurses, 3 senior physicians, 3 registrars/residents), of which 47 responded (approximate 37% response rate) and 46 provided sufficient data for analyses. Demographics are presented in Table 1. The majority of participants were female (94%) and 40 years or over in age (76%). Most were in a nursing role (90%) with approximately equal proportions worked primarily in an inpatient (43%) and community setting (50%). On average the sample had a decade of experience ($M=10.15$, $SD=9.91$). Only two participants (4%) indicated that they were involved in recruitment to the feasibility trial of the self-help intervention that had recently finished at the inpatient sites.

Differences in outcome variables based on demographics were examined. Results showed that staff working primarily in a community setting showed significantly higher confidence scores in identifying and managing carer psychological distress ($n=23$, $M=3.16$, $SD=.57$) than staff working primarily in an inpatient setting ($n=20$, $M=2.77$, $SD=.52$; $t_{41}=2.38$, $p=.02$). It is possible that longer duration in the current role could potentially lead to greater confidence in skills and knowledge. To explore this further we used an independent t-test to determine whether community staff had longer duration in their current role, on average, compared to inpatient staff. However, results showed no statistically significant difference ($p>.05$). No other demographic analyses were statistically significant ($p>.05$).

Outcome descriptives

Acceptability of self-help intervention. Most participants indicated that they had at least “a little experience” with self-help intervention ($n=33$, 72%). The mean acceptability score indicated that self-help intervention for carers was at least moderately acceptable to clinical staff on average, being past the midrange of “neither agree nor disagree” ($M=3.42$, $SD=.48$, range=1-5). Approximately two-thirds of participants agreed or strongly agreed that guided self-help is an acceptable ($n=30$, 65%) and an effective ($n=29$, 63%) approach for carers. Similarly, approximately two-thirds of participants ($n=31$, 67%) indicated that they would be willing to suggest guided self-help to carers that they saw, with none or very few ($n=2$, 4%) indicating disagreement. One third agreed or strongly agreed that risk in undergoing guided self-help was a concern ($n=15$, 33%) while half neither agreed nor disagreed ($n=23$, 50%).

Confidence with skills and knowledge in assessing carer psychological distress. Mean confidence scores indicated that clinical staff, on average, were mostly confident with their skills and knowledge in identifying and managing carer distress ($M=2.99$, $SD=.56$, range=1-4). Table 2 shows the proportion of participants scoring low (scores 1-2) versus high (scores 3-4) for each confidence item. It is evident that the vast majority of staff showed high confidence in most skills or knowledge areas. The most notable exception was the “ability to inform and educate carers about psychological distress” in which half of staff indicated low confidence. Other areas of relatively low confidence involved: discussion of referral or support options (35%), supporting those close to carers with abnormal levels of distress (37%), monitoring changes in psychological distress (39%) and responding to expressions of helplessness or hopelessness (33%).

[INSERT TABLE 2 HERE]

Attitudes toward PGD. Mean scores on positive ($M=3.89$, $SD=.68$, range=1-5) and negative ($M=3.22$, $SD=.81$, range=1-5) attitudes toward a PGD diagnosis were both past the scale midpoint, indicating the simultaneous presence of both positive and negative attitudes toward PGD. Table 3 shows the mean scores and proportion agreeing to the PGD attitude items. The vast majority of clinical staff agreed or strongly agreed that diagnosing PGD would increase carer likelihood of getting the best help (85%), while three-quarters agreed or strongly agreed (74%) that PGD is distinct from other disorders and should be recognised as a psychological disorder. Nonetheless, staff opinions were more split regarding how a PGD diagnosis reflects pathologisation of normal reactions. Notable proportions agreed that recognition of PGD may lead to pathologisation of “normal” grief (41%) and reflects a trend in psychology to pathologise normal reactions (43%).

[INSERT TABLE 3 HERE]

Attitudes toward grief interventions. Staff attitudes toward grief intervention were positive on average, with the mean score slightly above the “agree” response anchor ($M=4.18$, $SD=.59$, range=1-5). The majority of clinical staff disagreed or strongly disagreed that professional help for grief should always be a last resort ($n=45$, 98%) and that any psychological intervention disrupts a natural grieving process ($n=38$, 83%). Instead, the vast majority agreed that psychological intervention can be valuable to those who are struggling with their grief ($n=42$, 98%). However, while most staff disagreed ($n=28$, 61%) that it was always best to leave people to move through grief in their own way and time, another quarter neutral on this item (neither agreed nor disagreed, $n=12$, 26%).

Correlations

Table 4 shows results from the correlation analyses on mean total scores of the study variables. Higher acceptability ratings of self-help for carers were associated with more positive attitudes toward PGD as a diagnosis and intervention for grief. No other correlations were statistically significant ($p > .05$), although there was a trend for greater levels of confidence in skills and knowledge being associated with more positive attitudes toward intervention for grief ($p = .06$).

[INSERT TABLE 4 HERE]

Since an assumption of this study was that clinical staff may be less likely to refer to a guided self-help intervention for PGD if they have negative attitudes toward PGD (e.g., pathologising grief) we correlated the item “I would be willing to suggest guided self-help to carers I see” with the two PGD attitudes scales. It was found that holding more positive ($r=.34, p=.02$) and somewhat surprisingly *more* negative ($r=.30, p=.02$) attitudes toward PGD were both significantly related to greater clinical staff willingness to suggest guided self-help to carers.

Discussion

This study found that clinical staff were overall positively oriented toward self-help for carers, accepting of PGD as a diagnosis whilst concurrently holding reservations, approving of intervention for grief, and largely confident in their skills and knowledge to identify and manage carer psychological distress appropriately. These results are useful in informing the

research team of a few broad issues to be considered should a self-help intervention for carers be implemented in the health care service.

Clinical staff perceptions of the acceptability of guided self-help intervention for carers showed that the majority feel positively toward it, although it would be beneficial to explicitly identify potential risks and outline how to manage them. Likewise, the attitudes of clinical staff toward a PGD diagnosis and intervention for grief were overall positive, with the majority indicating that grief intervention is valuable and that a PGD diagnosis would help carers get the best help possible. The proportion supporting the inclusion of PGD as a diagnosis (74%) is strikingly similar to those found amongst international members of the general public (75%; Breen et al., 2015) and Australian psychologists and counsellors (73%; Ogden & Simmonds, 2014). However, negative attitudes toward a PGD diagnosis were also prevalent in the current sample, although to a lesser degree. Notable proportions expressed concern about the potential for pathologisation of grief (41%) and reduced consideration of individual differences in grief expression (28%), although these proportions are considerably less compared to those reported for psychologists and counsellors (56% and 55% respectively; Ogden & Simmonds, 2014). While overall it was positive PGD attitudes that were associated with acceptability of guided self-help for carers, it is important to note that both positive and negative PGD attitudes were associated more specifically with the willingness to refer carers to such an intervention. On the surface, this is a somewhat contradictory finding. However, it could be that concerns about the pathologising effects of PGD are intertwined with overall concerns about the negative consequences of PGD on carers. If this were the case, then clinical staff would be more inclined to refer carers in need to self-help interventions for PGD. Similar to this, a qualitative study among social workers found that many participants held to both medicalised/diagnostic and contextual (individual interacting with their environment) views of mental health; participants maintained that

withholding a psychiatric diagnosis when truly indicated would result in equivalent disservice to an individual's care as attributing a problem resulting from contextual issues to internal dysfunction (Probst, 2013). Alternatively it may be that self-help interventions as opposed to face-to-face psychotherapy is considered a particularly nonpathologising approach for helping carers. Thus, those with concerns about the pathologising consequences of PGD as a diagnosable disorder may view self-help approaches as more appropriate. At this stage we can only speculate, but future research may be able to test these hypotheses. Pragmatically, the findings suggest that in order to optimally promote referral to the intervention among clinical staff, it may generally be effective to emphasise the benefits of a PGD diagnosis without needing to address the negative concerns about PGD pathologising grief.

Clinical staff indicated generally satisfactory levels of confidence in their skills and knowledge. At least three-quarters of participants indicated high confidence in differentiating between normal and abnormal psychological distress in carers and knowing when it is time to raise concerns about carer distress and thereby initiate referral for support. However, a third of participants showed low confidence in *discussing referral or support options* for abnormal psychological distress with a carer. Given the clinical staff in this study were on the frontline in interacting with patients and their carers, it would be advantageous to increase skills and confidence around these issues.

It is interesting that staff working primarily in the community showed significantly higher confidence compared to staff working primarily in the inpatient unit. Results indicated this was not likely to be due to longer duration spent in the current role for community staff compared to inpatient staff. Thus, we can only speculate about the source of differences in confidence between community and inpatient staff. For example, some prior research raises the possibility that the difference in confidence are due to training differences (McCabe, Russo, Mellor, Davison, & George, 2008). Using a similar confidence scale, McCabe and

colleagues (2008) found that professional carers who had received previous training in depression had greater levels of confidence in identifying and managing depression in elderly patients than carers who had received no training. It is also possible that the difference observed in the present study is attributed to the greater level of contact community staff have with carers. While these suggestions are speculative, further research might be able to clarify these issues in order to ensure continuity of confidence across community and inpatient settings.

There are a number of limitations to this study to be noted. The passive recruitment method may have introduced selection bias and thus the results cannot be confirmed as representative of all clinical staff. Generalisability is also limited by the small sample size and by clinical staff being recruited from the same broad health service and comprised mostly of nurses. Future research would benefit from recruiting across different health services and broadening the staff composition, particularly to include allied health. This would also allow us to compare responses from mental health and non-mental health clinical staff, which have been shown to differ at least in PGD attitudes based on the comparisons with psychologists and counsellors highlighted above (Ogden & Simmonds, 2014). Also, although we adapted measures from prior research, there is little reliability and validity data for most of these measures. Future research in refining and validating measures to evaluate clinical staff attitudes is needed.

It is also important to note that most participants would not have had much opportunity to observe PGD in carers because contact ordinarily ceases following the death of the patient. Thus, these results more likely reflect clinical staff opinion about PGD in general than how it specifically relates to carers. However, this enabled clinical staff to base their responses from a richer and broader knowledge base from their own life experience of grief. Related to this, these results permit us to only consider how acceptability of guided self-help are associated

with attitudes toward grief specifically (not other common presentations of depression or anxiety) and thus are limited in applicability to interventions for grief. Nonetheless, grief is an important focus given the controversial nature of its diagnosis and perceived needs for intervention.

Conclusions

The results indicate that clinical staff were largely positive about self-help intervention and grief intervention for carers, and thus generally likely to act as key allies in implementing the intervention. Clinical staff held both positive and negative attitudes toward PGD as a diagnosis, but both orientations appeared to be associated with greater willingness to refer to self-help for carers. To optimize referral, results suggest that educating staff about the benefits of a PGD diagnosis and the logistics of the referral process to the intervention would be helpful. Future research would benefit from examining clinical staff attitudes toward different diagnoses and treatment approaches in order to better understand how to work alongside staff when implementing interventions in their health service.

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