

# Investigating Involvement in Bereavement Support by Palliative Care Volunteers

---

Kate Bowman & Alex Huntir, Palliative Care NSW

## Introduction

This study looks into the ways in which Palliative Care Volunteer Services in NSW offer support, if any, to caregivers who are bereaved. Palliative care volunteers exist to improve palliative care outcomes, and palliative care is interested in the experience of living, dying and grieving. For these reasons, the palliative care volunteer service has an interest in how the caregiver experiences their loss and subsequent bereavement.

In this report a reference to a 'caregiver' is a reference to a person close-to and highly impacted by the subsequent death of the patient.

In discussing bereavement we acknowledge that responding to the full existential dimensions of grief and bereavement is a specialised discipline with which this paper does not attempt to critique or engage. Rather we are interested in volunteer involvement in programmes that have been designed and labelled as 'bereavement' by experts in the field, by asking the question: 'how do volunteers experience their involvement in programmes designed to respond to bereavement'?

The literature indicates that the experience of grief and bereavement by the caregiver is mediated and affected by many factors such as the perception of the caregiver of the care provided, the perception of the caregiver of the patient's experience of symptom distress, the functionality/dysfunctionality of the caregiver's family dynamic, and the nature of psychological support following death [1].

*'How people die remains in the memory of those who live on'. Cecily Saunders, founder of the modern palliative care movement.*

The personal experience of grief is not the only event to impact on caregivers. Research indicates that the pre-death caregiving period is often accompanied by 'anxiety, depression, social isolation, social stigma, social rejection, family breakdown, premature job loss, financial strain, spiritual dilemmas or crises, even suicide, among a host of other troubles' [2] and that the post-death experience of bereavement by caregivers can be associated with complex psychological, physical, social and economic outcomes [3], [4], [5].

For these reasons formal bereavement support is offered by most palliative care services in Australia, with a 2008 study indicating that 95% of the 236 palliative care services studied provided some form of support including a telephone call (offered by 86%), memorial service, (66%), letter (55%), anniversary card (53%), group sessions (31%), information package (5%) and informal gatherings (4%) [6].

Breen et al [2] studied the experience of bereaved caregivers and identified opportunities for volunteer input, noting that:

*'While most bereaved people do not require professional counseling, all would benefit from appropriate information and compassion...Additionally, approximately one-third of the bereaved caregivers would benefit from opportunities to reflect upon their loss, which could*

*be provided by trained volunteers and bereavement support groups. For them, a brochure or telephone call alone might not be sufficient, yet they do not require specialist intervention.'*

Although anecdotally we have been aware of volunteer involvement in memorial services, bereavement letters and phone calls and in an extension of their support role into the bereavement period, there is no studied understanding of bereavement involvement by volunteers. Our comprehensive 2014 study of palliative care volunteering in NSW noted bereavement involvement but didn't attempt to quantify or qualify such involvement [7].

In surveying palliative care volunteers it is appropriate to acknowledge the important contribution of other volunteers (those not self-identifying as palliative care volunteers) in bereavement-type support in ways which may be incidental to their roles such as some Meals on Wheels volunteers and people who volunteer with Lifeline, the CWA and local community centres [8]. Although the experiences of these volunteers is not a focus of this report we note that they contribute to a community-led response to bereavement support that has the potential to mitigate higher levels of distress, improve caregiver outcomes and to increase the size of caring networks [9].

## Method

Palliative Care NSW surveyed grief and bereavement support volunteers from various palliative care service providers across the state in order to better understand what the individual volunteer role entails.

NSW service managers were initially sent an email to help identify which organisations had volunteers in grief and bereavement support that could later be contacted to participate in the survey. As very few responded, the survey link was sent out to all the palliative care providers in the hope of obtaining as much data as possible. Service managers were asked to pass on an email to their volunteers involved with providing grief and bereavement support, inviting them to participate in the study.

The online survey was developed using SurveyMonkey, consisting of 30 questions of varying formats. Closed questions were predominantly used throughout the survey in multiple-choice format, however, Likert scales were also incorporated. Several open-ended questions allowed respondents to detail their individual experience in the role. External experts in bereavement and volunteer management fields were asked to validate the questions to ensure overall appropriateness and accuracy prior to field use. The survey was open for a total of 2 weeks, with a reminder email sent out after 1 week.

In completing the survey, volunteers were required to self-identify as being involved with grief and bereavement support. Participants were not required to identify themselves or their service within the survey and informed that their responses would be de-identified for reporting and publication. A total of 29 respondents completed the survey.

## Findings

*What role do volunteers play in grief and bereavement support?*

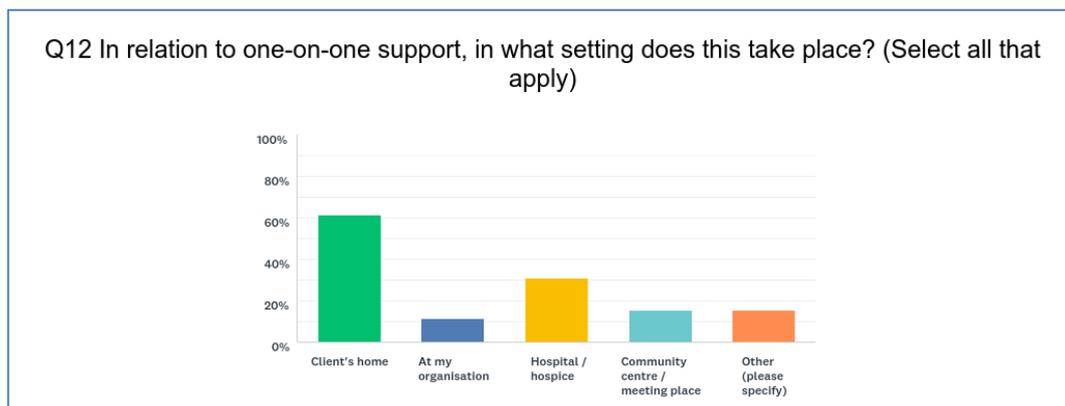
The survey found that volunteers were involved variously in memorial services, anniversary cards, the provision of health-service related information, informal group support and one-on-one contact with clients.

The most common involvement in bereavement support was one-on-one contact with clients (89% of respondents). The frequency of involvement varied, with 62% indicating that they were involved in one-on-one support once a week, 17% indicating that they made fortnightly to monthly contact and 10% indicating that they made themselves available 'as required'.

*'Support varies with the clients/carers. I would normally see the client weekly/fortnightly. If the client passes away, I would support the family frequently at first but after a month or so this may be reduced to weekly check-ins depending on the need. Grief is different for everyone.'*

Although most one-on-one contact was face-to-face, 17 respondents indicated telephone contact, 2 respondents said they made contact via mail or email and 1 respondent said they used Facebook to keep in touch with a client.

Contact usually occurred in the client's home (62%) but could also be at the hospital/hospice, at their organisation's location, community centre or in another meeting place such as a café or a funeral service.



Involvement with memorial services was reported by almost two-thirds (64%) of respondents, typically by attending or helping to organise and cater for the events. Memorial services might be held annually or at regular intervals and are intended as an opportunity for remembrance of people who have died, and as an opportunity for shared support through the common experience of loss. Family and carers of clients that have died are invited to attend the ceremony, along with staff members who have supported patients in their end-of-life.

Group support was offered by a 25% of respondents in both formal and informal settings. The comments offered by respondents indicated that 'coffee clubs' were popular as they provided a relaxed environment for people to talk and make connections with others:

*'As a member of a bereavement support group self-run with twice monthly informal meetings for coffee and friendship.'*

*'At our weekly Coffee Club, there may be a number of palliative care people together.'*

In more formal settings, volunteers were instrumental in facilitating structured Bereavement Support Groups run by qualified bereavement counsellors attached to their palliative care service. These groups may take a more- or less- formal approach to support depending on the needs of participants.

*‘Our service usually hosts a couple of events each year to which clients and carers are invited. Usually, this involves a Morning Tea with relevant Guest Speaker and an opportunity to talk with clients/carers in a supported setting.’*

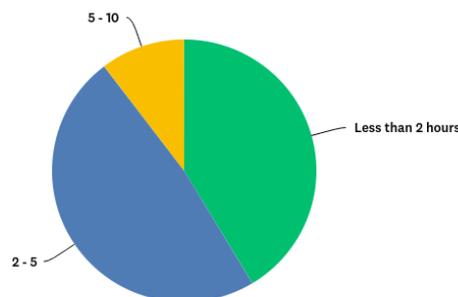
Involvement in ‘anniversary card’ programs was less commonly reported (7%) as was the provision of ‘health-service related information’ (10%). These are explained below.

Anniversary cards are intended to make unobtrusive contact with bereaved carers by sending them a card (with or without enclosed information) at scheduled intervals after death. Volunteers assist by writing and addressing cards and attending to the mail-out process.

The provision of health-service related information is a more proactive role in offering information on topics such as constructive grief, or on how to contact community services and government agencies (Centrelink, community transport, respite) or funeral services in the area. One respondent reported the promotion of advance care directives as part of this role.

The study also quantified how much time was devoted by volunteers to bereavement support. About 42% of respondents indicated being involved up to 2 hours a week, 48% indicated an involvement between 2 to 5 hours a week and some 10% indicated they contributed up to 10 hours a week.

Q2 On average, how many hours a week do you contribute to volunteering in grief and bereavement support?



The number of hours spent volunteering was often contingent upon the nature of the support provided and the involvement of the volunteer in other support roles in palliative care. Some 17% of respondents reported performing only grief and bereavement support, whereas 65% reported that grief and bereavement support was just one part of their regular palliative care volunteer role. Another 17% of respondents reported that they only performed this role occasionally.

The majority of respondents (75%) saw less than 6 clients per year, with only 10% saying that they saw between 12 and 40 clients. The respondents who reported seeing between 10-20 clients did so monthly. One of these volunteers was involved with follow-up bereavement support for carers six

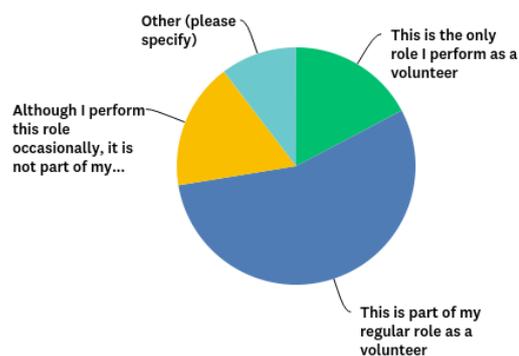
weeks after their loss. Their support was provided over the phone or face to face at the hospital, organisation head office, or other meeting place rather than in the client's home.

The respondent who saw 40 clients per year volunteered at the hospital more than once a week. With a post-graduate degree in counseling, she understood her role to be purely in grief and bereavement support. She did this by being the 'trolley dolly' and volunteering at the hospital kiosk. Offering hospitality provides opportunity to put people at ease and get them talking.

Another respondent, by going room-to-room at a hospital, estimated they saw 100 patients and their families per year. Another said they helped 200 people a year by referring them post-death to other support services.

Those respondents who indicated seeing less than 6 clients appeared to have roles which were more intensive and relational in nature, typically seeing their clients face-to-face at least weekly in their client's home for social support and companionship. Some 73% indicated that they talked over the phone. Some 28% of respondents think of their visiting role as for social support or carer respite.

Q3 In relation to your role in grief and bereavement support, select one of the following options:



Through their comments respondents indicated that their main focus was to be there to visit, talk and listen:

*'Usually just allowing the person to talk through their concerns.'*

*'We often talk about the child and the good times we had together or I let the Mum just talk and I listen.'*

*'I am open to anything the client or carer may require, be it shopping, a drive, a trip to the nursery, a walk along the beach or just a trip to the local coffee shop. One client likes me to make a batch of scones for them. Documenting a life story is also requested.'*

Likewise, through their comments the respondents indicated that they believed they were an important source of information and referral to other services:

*'Giving down to earth help and information on grief.'*

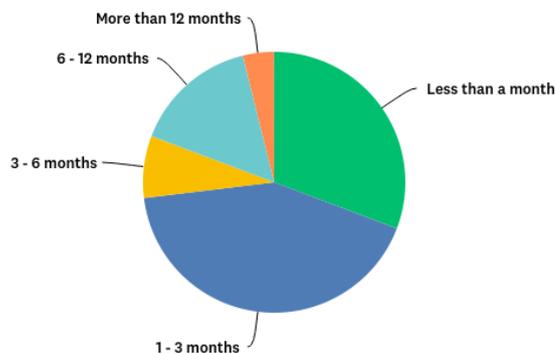
*‘Active listening; emotional support; empathy; referral to pastoral care or relevant external services.’*

While it is no doubt helpful to provide practical support such information and referral to other services, this study has found that it is the ‘just being present’ part that is the most important. Regular contact with the same clients builds rapport. Sharing time at a cafe, going for a walk or meeting over a cup of tea creates a relaxed and intimate space in which people are more comfortable to share their experience with the volunteer. Active listening is clearly a crucial component in supporting the bereaved.

This study was also interested in understanding if volunteers typically supported a patient nearing end of life and then continued to offer bereavement support to their family after they have died. Some 25% of respondents said this never happened, while another 43% said they do so only sometimes or occasionally. Only 31% of respondents indicated that it was usual for their role to include post-bereavement support to the same family.

The length of time volunteers maintained contact with each client post-death was also of interest. Some 73% of volunteers kept in contact for up to 3 months but beyond that initial period contact drops away significantly. Only 2 respondents specified one-to-one bereavement follow-up as part of their role. Volunteers who always or usually supported a patient nearing their end of life and then continued to offer the family support after they have died maintained this relationship for longer. Some 57% of them were still in contact with the family over three months later. In one case, they stayed connected for more than a year.

Q18 In relation to grief and bereavement support, how long do you typically maintain contact with each client post-death?



*Who commits their time to grief and bereavement support, and why?*

One section of the survey included questions intended to provide a demographic snapshot of the volunteers involved in bereavement support. Responses came from all over New South Wales including from regional (42%), rural (31%) and metropolitan (27%) areas. This information helps to build a picture of volunteers providing this type of care.

All the volunteers in this survey were over the age of 40 and, with the exception of one male respondent, were female. The overwhelming majority (92%) were between 50 and 80 years of age with the largest cohort (38%) in the 71-80 year bracket. Some 62% of respondents describe

themselves as retired, with 7 respondents working either full or part-time, 1 studying and 2 indicating home duties.

Only 1 respondent indicated involvement for less than six months, with almost half (48%) of those in the study indicating involvement of between 1 and 5 years, and another 30% with more than 5 years' involvement.

Volunteers were asked to describe what sort of specialist training or preparation they had undertaken for this role. All palliative care volunteers go through some kind of induction training provided by their volunteer service which usually includes a module of grief and bereavement. Only 17% of respondents reported the standard induction training as a source of preparation for their role:

*"Only our 40-hour volunteer training and what we learn from each other in monthly meetings."*

Some 38% of respondents said they had some sort of specialist grief and bereavement training through organisations such as the *NALAG Centre for Loss and Grief, Seasons for Growth, The Bereavement Care Centre, The Compassionate Friends* or *The Cancer Council*. Some 10% said they had a formal counselling experience and 17% had a background in nursing. Some 28% of respondents felt that they brought translatable skills from related fields such as aged care, pastoral care, community or social work.

Overall, this group was well educated with 69% indicating they held tertiary qualifications or which 35% were university qualifications, averages which are higher than the Australian average [10]. Of these some 19% indicated holding a postgraduate degree with 1 in counseling and 1 in pastoral care mentioned by name.

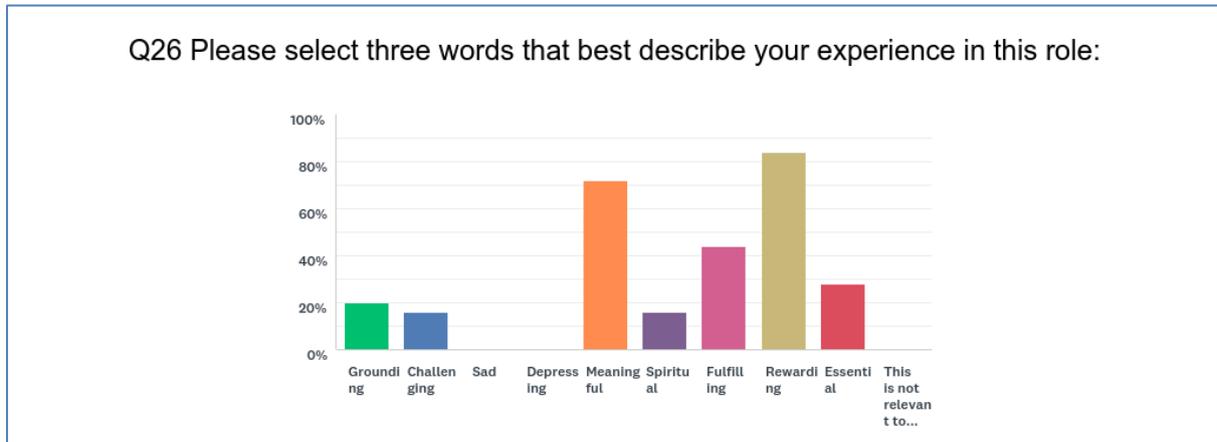
This research explored what motivated someone to volunteer for a role of this nature. The study found that the most common reason people decided to volunteer in this role was that they thought they had the skills relevant to enable them to contribute meaningfully (55%). Some 24% of respondents revealed that they had experienced the death of a loved one and desired to help others, with 10% indicating a desire to help and care-for people wherever help is needed, and 7% having a particular desire to support a family in need.

When asked how long they intended to keep volunteering at their current organisation most respondents (38%) were unsure. Given the median age of the volunteers this could be attributed to uncertainty about future capacity or opportunity. Some 23% of respondents still said they expected to continue volunteering for another 1 to 5 years and another 15% indicated the intention to be active for a further 5 to 10 years. The finding that 1 in 3 planned to continue with volunteering for at least the next 5 years (despite most of them being over 70) demonstrates a high level of commitment in the group.

*What experiences matter the most to volunteers?*

Volunteers that choose to work in palliative care must possess well developed social skills and have the appropriate disposition to work with people during an extremely difficult time. Death, dying and grief are everyday realities. Some might assume this to be a very sad environment but this research showed that that is not the case for this group. When volunteers were asked to select three

words that best describe their experience of their role, *rewarding* was selected as number one by far with 84% in agreeance. *Meaningful* came second with 72% followed by *fulfilling* with 44% of the vote. (Note: Answer percentages = >100 as respondents could identify more than one selection.) Not one single person selected *sad* or *depressing*.



Everyone felt their work made a significant difference with over three-quarters of respondents (76%) rating the impact they had made as a volunteer on their clients as high to very high.

Respondents were asked about the more challenging features of their role and there were a diverse range of answers to this question. The common themes to emerge included: loss, intuition, communication, time, emotion and attachment:

*'Being left with no further contact re client or family (they moved to a hospice in Sydney)'*

*'Recognizing whether patients wish to be disturbed or not.'*

*'Trying to say the right thing'*

*'Getting to people early in the grief experience''*

*'Seeing person going through necessary grief journey, person being able to trust'*

*'When you make a connection and they die'*

*'Maintaining boundaries between myself and the family'*

Through their comments the participants appeared to find their role rewarding and enjoyed bringing notions of comfort and hope to their clients. For some, the most rewarding part of bereavement support was the deep connection made with clients:

*'Meeting the person where they actually are in themselves and being with them without false words and masks'*

*'Being able to listen to people and give them the experience of really being listened to and understood with compassion.'*

Just knowing they had helped was enough reward for some volunteers:

*'Being able to offer a pleasant distraction from their health problems.'*

*'Helping a very busy family in need of everyday things that are made so hard due to a sick child.'*

Others were pleased to report their efforts had brought about a noticeable benefit:

*'Seeing the positive changes in our clients as we help them with skills to live their lives after loss.'*

*'Seeing families at ease with loss of a loved one after having Palliative Care as a part of their journey.'*

Some realised that there is a community of others involved with and affected by palliative care:

*'Number of like-minded people willing to assist others.'*

*'The friendship and the caring.'*

*'Feeling comfortable with the different ways people cope with grief.'*

Finally, several of the more reflective comments revealed the existential impact on the lives of several participants as a result of their involvement in this particular volunteering role:

*'That a good death can be a wonderful experience.'*

*'Watching how humans remain dignified to the end.'*

*'Most unexpected would be how much I have learnt about myself personally, how much I have learnt about the human capacity for resilience in difficult times, and how little as a community we know and understand about grief and bereavement.'*

*'This work has taught me patience and improved my listening skills and released my feelings of compassion for those other than my family and friends.'*

## Discussion

This study has attempted to present a picture of the way in which palliative care volunteers experience their involvement in grief and bereavement support.

In particular the report has highlighted that the most typical role of grief and bereavement support volunteers is performed through an informal interaction with clients in one-on-one meetings usually in the client's home.

Palliative care is not only about living and dying well, but also about grieving well. By building a rapport with clients and giving them the space to share, relive and express their experience of grief and loss the palliative care practitioner is able to mitigate clients' distress and improve outcomes. The involvement of volunteers in one-on-one interactions with clients tacitly affirms the trust placed in volunteers by paid staff by involving volunteers in a form of support which lies at the heart of the philosophy of palliative care.

We acknowledge that the study was necessarily limited to those services which were already actively involving volunteers in palliative care. While the research shows that most palliative care services in Australia offer grief and bereavement support this study did not attempt to quantify the proportion of volunteer services involved in that support.

Nevertheless the study found that, where volunteers were involved, their participation was not insubstantial if measured by the number of clients seen per year, the number of hours spent per week or the level of qualification of the volunteers involved.

We also acknowledge that the study made no attempt to measure or quantify the quality of interactions, the detail or training or the measurement of competence for volunteers involved in this field of activity. Whether this would be valuable or meaningful is beyond the scope of this report, but we do note that as a self-rated measure of impact, the participants overwhelmingly indicated that they believed that they made a meaningful contribution to the wellbeing of the client.

## End notes

### **The Volunteer Support Services Programme**

This paper has been prepared as part of the Volunteer Support Services Program which is hosted by Palliative Care NSW and funded by NSW Health. The Volunteer Support Services Programme seeks to champion the work and interests of Palliative Care Volunteer Services and volunteers in NSW ([www.volunteerhub.com.au](http://www.volunteerhub.com.au)).

### **Acknowledgements**

We acknowledge the contribution of intern Natalie Kerr who contributed to the survey as part of her placement with us through Macquarie University. We also acknowledge the assistance given by Kristin Bindley (Social Worker and Bereavement Counsellor) from WSLHD in helping to validate the survey questions. Thank you to everyone who responded and contributed to these findings.

### **Suggested citation**

Bowman, K. & Huntir, A. (2017). *Investigating Involvement in Bereavement Support by Palliative Care Volunteers*. Palliative Care NSW, Surry Hills.

## References

- [1] Gauthier, L. and Gagliese, L. (2012). Bereavement Interventions, End-of-Life Cancer Care, and Spousal Well-Being: A Systematic Review. *Clinical Psychology: Science and Practice*, 19 (1), p72-92.
- [2] Breen, L. J., Aoun, S. M., Rumbold, B., McNamara, B., Howting, D. A. & Mancini, V. (2015). Building Community Capacity in Bereavement Support: Lessons Learnt from Bereaved Caregivers. *American Journal of Hospice and Palliative Medicine*, 34(3), p275–281.
- [3] Stroebe, M., Schut, H. and Stroebe, W. (2007). Health outcomes of bereavement. *Lancet*, 8, 370 (9603), 1960-73.
- [4] Kellehear, A. (2013). Compassionate communities: end of life care as everyone's responsibility. *Q J Med*, 1071-1075 doi:10.1093/qjmed/hct200.

- [5] Essue, B.M., Beaton, A., Hull, C., Belfrage, J., Thompson, S., Mechen, M. and Gillespie, J.A. (2015). Living with economic hardship at the end of life. *BMJ Supportive and Palliative Care*, 5, 129-137.
- [6] Breen, L. J., Aoun, S. M., O'Connor, M. & Rumbold, B. (2014). Bridging the Gaps in Palliative Care Bereavement Support: An International Perspective. *Death Studies*, 38, p54-61.
- [7] Hansen, L. & Huntir, A. (2014). *A Snapshot of Palliative Care Volunteering in NSW 2014*. Palliative Care NSW, Surry Hills.
- [8] Bowman, K. (2016). *Investigating Understandings of Palliative Care within Community Volunteer Groups*. Palliative Care NSW, Surry Hills.
- [9] Sallnow, L., Richardson, H., Murray, S.A. and Kellehear, A. (2016). The impact of a new public health approach to end of life care: A systematic review. *Palliative Medicine*, 30 (3), 200-201.
- [10] Australian Bureau of Statistics. (2017). *Education and Work, Australia, May 2017*. Issue 6227.0. Available at <http://www.abs.gov.au/ausstats/abs@.nsf/mf/6227.0> Accessed online 7/12/2017.