

POSTER PRESENTATIONS

Exhibition Hall – times yet to be determined

Do we know what they need? Identifying young carers and young adult carers needs

Presenters and authors: Marianne Frech, RN, PhD candidate (Swiss National Science Foundation SNSF), learn&care; Professor Dr Agnes Leu, programme director learn&care; and Dr Corinna Jung, senior researcher learn&care, Careum Research, Kalaidos University of Applied Sciences, Zürich, Switzerland

In Switzerland there is still little awareness towards the vulnerable group of caregivers under 18 years among professionals, the target group itself as well as the public. Findings from first young carers research projects highlight the challenges these young people face every day. Qualitative and quantitative data from interviews with young carers, focus groups and an online survey conducted with professionals working in education, health care and social services now provide first results on young carers and young adult carers in Switzerland:

- What kind of support do young carers need?
- What do professionals with different scopes of practice need in order to support young carers?

The results show different perceptions of these young people with caring responsibilities and their perceived needs for support.

Comparing the data from our national research with young carers and professionals, we can frame their individual needs for support and point out areas of differences in order to facilitate support options in Switzerland. Our findings are embedded in the context of the international research. We highlight the challenges of developing target-oriented support based on country specific research findings.

Stigma experienced by family carers

Presenter: Liam O'Sullivan, Executive Director, Care Alliance Ireland

Author: Zoe Hughes, Policy and Research Officer, Care Alliance Ireland

Many family carers are happy for others in their circle of friends and family to be aware of their caring responsibilities. This is often easier when the 'reason' the person being cared for requires care is a condition, which is likely to elicit a particularly empathetic response – such as dementia, or a significant medical condition. However, not all conditions that necessitate family members becoming family carers necessarily fall under this category (mental health, HIV, addiction, COPD). For many carers, stigma can be a significant factor, which can have an impact on their wellbeing. It can also impact on their willingness or ability to access supports needed throughout their caring journey.

Whilst the notion of 'stigma' has developed and changed – and is still under debate – since it was first developed in the 1960s, in general it can be seen as set of misguided opinions about a group of people, built upon assumptions which have developed over time. The notion of stigma, as it relates to mental health and disability is usually discussed in the context of the person receiving care- yet it is clear that those who provide significant levels of care also experience stigma related to a myriad of other factors.

The objective of this poster presentation is to outline the key types of stigma experienced by Family Carers (via literature review) including data from a general survey undertaken by Care Alliance Ireland in 2015 of 800 family carers. It is clear there are issues of stigma, which have not yet been addressed by research or indeed by support organisations, yet are experienced by many family carers. This is an internationally relevant topic, which speaks to a lesser discussed challenge for support organisations, who may have little to no experience in discussing these sensitive topics with family carers.

Do Leaflet Drops and Targeted Social Media Ads Increase Carer Identification

Presenter and author: Liam O'Sullivan, Executive Director, Care Alliance Ireland

In April 2016, Ireland's Census of Population took place. Since 2002, a specific question in the Census has attempted to capture the prevalence and (more recently) the intensity of Family Caregiving.

Within the advocacy/civil society area in representative democracies, there is a long history of placing value on awareness raising of causes as means to improve the situation of those they seek to represent. The carers movement is no different in this regard and has for a long time placed emphasis on carer identification. Not-for-profit organisations regularly seek to justify their role, funding and existence by claiming that awareness raising is a key aspect of their work. In doing so they argue that this supports carer wellbeing and that in addition it supports the resourcing, and accessing of, specific carer support services.

Data from previous population Censuses in Ireland have over time demonstrated an increasing level of carer identification, over and above that which would have been expected due to demographics/medical advances alone. This suggests that carer identification interventions can be effective, notwithstanding the impact of other cultural influences over time. No research however has been conducted to date to test this hypothesis.

This poster tells the story of a small scale study/specific intervention that took place in the days running up to the Census night; namely a suburban house to house leaflet drop (n = 269) and use of geographically targeted paid social media posts (Facebook; reach 1,763) together with a similar social media intervention targeted to two other geographical areas in Ireland (one rural, one mixed; Facebook, reach 1,989 and 1,076 respectively).

Following the release of national as well as local area population Census statistics in July 2017, we reviewed the impact, if any, such small scale and local interventions had on carer

identification, as measured by changes to self-reported caregiving through completion of the Census form in those particular geographical areas.

We will discuss the possibilities for future interventions that impact on carer identification.

Carers NSW 2016 Carer Survey

Presenter and author: Timothy Broady, Senior Research and Development Officer, Carers NSW, Australia

Every two years, Carers NSW conducts a survey of all carers across the state. This survey investigates issues such as wellbeing, employment, service access, and social support, and seeks carers' opinions on important political matters affecting them. In 2016, over 2,000 carers and former carers completed the survey, making it the largest survey of carers we have ever conducted. This poster highlights some of the main findings from this project, including demographic characteristics, and many of the challenges faced by carers as they support family members and friends in the community.

Carers NSW 2016 Carer Survey – Aboriginal and Torres Strait Islander carers

Presenter and author: Timothy Broady, Senior Research and Development Officer, Carers NSW, Australia

Every two years, Carers NSW conducts a survey of all carers across the state. This survey investigates issues such as wellbeing, employment, service access, and social support, and also seeks carers' opinions on important political matters affecting them. In 2016, over 2,000 carers and former carers completed the survey, making it the largest survey of carers we have ever conducted.

This poster highlights some of the main findings from this project as they relate to those participants who identified as Aboriginal and/or Torres Strait Islander, including demographic characteristics, and many of the challenges faced by carers as they support family members and friends in the community. The poster particularly highlights how the experiences of Aboriginal and Torres Strait Islander carers in NSW compares to those from a non-Indigenous background.

Carers NSW 2016 Carer Survey - Lesbian, Gay, Bisexual, Transgender and Intersex carers

Presenter and author: Timothy Broady, Senior Research and Development Officer, Carers NSW, Australia

Every two years, Carers NSW conducts a survey of all carers across the state. This survey investigates issues such as wellbeing, employment, service access, and social support, and also seeks carers' opinions on important political matters affecting them. In 2016, over 2000 carers and former carers completed the survey, making it the largest survey of carers we have ever conducted.

This poster highlights some of the main findings from this project as they relate to those participants who identified as lesbian, gay, bisexual, transgender, and/or intersex (LGBTI), including demographic characteristics, and many of the challenges faced by carers as they support family members and friends in the community. The poster particularly highlights how the experiences of LGBTI carers in NSW compare to those who do not identify as LGBTI.

Having an impact: Supporting high quality family carer training

Presenter: Liam O'Sullivan, Executive Director, Care Alliance Ireland

Author: Zoe Hughes, Policy & Research Officer, Care Alliance Ireland

For most family carers, the onset of caring responsibilities is an unexpected development, and many family carers will have little to no experience of the various tasks and skills that are needed whilst in that role. Many support organisations offer training and educational opportunities for family carers. However, many also struggle with how to maximise the effectiveness of such training, how to measure impact and outcomes, and how to address specific implementation challenges.

Throughout 2016, Care Alliance Ireland delivered a project that aimed to address these gaps, involving a range of health and social care practitioners in Ireland. A three-stranded project was delivered, which included:

- a series of seminars in locations across the country
- a booklet that included feedback from participants as well as other practice resources
- a website that builds on the booklet material for practitioners and that hosts an interactive database of training (both online and face to face) available for family carers in Ireland (face-to face) and beyond (online).

This poster presentation focuses on the measurement of core skills and information gained by participants at the three seminars that took place in 2016. Baseline measurements were taken of participants' knowledge and awareness of current training available for family carers, their use of outcome focussed interventions, and their ability to provide high quality training and support interventions for family carers.

Over the course of the seminars, average measurements increased significantly, indicating an increased level of knowledge and confidence on the part of individuals. We posit that for practitioners in the field, this enables them to focus more on outcomes, rather than outputs. An additional outcome of this seminar series was an increased level of observable and self-reported cooperation and peer learning between a wide range of support organisations. By working with support organisations to increase their capacity to create and deliver these focussed training interventions, our objective to be of benefit to family carers accessing these supports has been achieved.

A collaborative approach to developing a carer garden

Presenter: Carol Sparrow, Regional Manager Carer Support Glandore Centre and Ruth Staker, Carer Support and Respite Centre Inc

Authors: Carol Sparrow, Tina Williams, Daniel Victory, Ruth Staker, Carer Garden Group

This poster presentation will showcase a place that is unique. Carers have a place where they nurture themselves while nurturing the garden: a space for relaxation, quiet activity and sharing. The garden is open seven days a week. The Glandore Carer Centre opened in June 2015 and the garden was launched in November 2015. We now have a thriving garden managed by a volunteer carer with the enthusiastic support of a carer garden group and staff of the Centre.

The garden was developed in partnership with Bunnings, Mile End who donated plants, trees, a birdbath and a garden bench and enabled Carer Support to run two fundraising sausage sizzles at their site to generate funds. Bunnings has committed to providing raised garden beds and plants into the future.

Carers have enjoyed weeding, soil preparation and planting of fruit trees in wine barrels along with an assortment of herbs, vegetables and flowers. The bench seat and birdbath sits under the shade of trees. A worm farm receives vegetable waste donated from staff lunches and provides the nutrients for the garden beds. We are achieving our aim of passing on the produce to carers - the garden group picked, pickled and took home a crop of cucumbers. They used herbs and chillis to make bottles of infused olive oil. All enjoy the fresh herbs, strawberries, lettuce, kale, corn, chillis, tomatoes, capsicums, cucumber, mandarins, limes, lemons and apples with rockmelon growing amongst the petunias, dianthus and snapdragons.

In late 2016 we gained a grant from Marion City Council to start an art project to be located on the rear wall, with permission from our neighbour. This mural/mosaic is being developed with two local artists who will collaborate with carers attending the garden group and other groups at the centre to develop the design and the approach to its creation. The concept is to portray caring in all its forms.

Conference attendees will have the opportunity to reflect on a dynamic collaborative partnership between Carer Support, other community agencies, carers and local artists, without which this wonderful initiative would not have been achieved.

A qualitative study of compound carers of people with intellectual disability

Presenter: Dr Attracta Lafferty, University College Dublin, Dublin, Ireland

Authors: Bianca van Bavel, University College Dublin, Ireland, Diarmaid O'Sullivan, Family Carers Ireland and Paul O'Mahoney, Family Carers Ireland

Assuming the role of 'compound carer' and having caregiving responsibilities for multiple family members can place significant demands on carers and negatively impact their quality of life. As people with intellectual disability are now living longer, the incidence of compound family caregiving is likely to increase, and a growing number of compound carers

are faced with the challenge of having to prioritise care needs. Very little is known about the nature and type of these compound caregiving situations, carers' experiences of transitioning to the compound caregiver role and the approaches taken by carers in response to the competing caregiving demands.

This poster examines the experiences of compound caregiving in families where there is a person with intellectual disability.

The research was conducted as part of a larger study on family carers of a person with intellectual disability. Compound carers who responded to a postal survey were invited to participate in a telephone interview about their experiences of having multiple caring roles and responsibilities. A total of 14 in-depth interviews were conducted with carers (4 males and 10 females), who, in addition to the care they provided to their relative with intellectual disability, provided regular unpaid care to another person requiring care due to a long-term illness, disability, frailty or other impairment. Interviews lasted between 40 and 75 minutes, were audio-recorded and transcribed verbatim. Data was thematically analysed and supported by NVivo software.

Findings highlighted the diverse nature of compound caregiving situations, which included parental (6), sibling (4) and sandwich (4) compound carers. Data analysis revealed the processes carers engaged in when transitioning to the role of compound carer and many carers indicated that they adopted an insular approach to caregiving to ensure continuity of care for their relative with intellectual disability. Service providers and policy makers need to take in account the unique caregiving circumstances of compound carers of people with intellectual disability, to ensure that they are sufficiently supported and so that care can continue to be provided by family members.

Home Visiting Services and Outcomes for Informal Home Carers in Japan

Presenter and author: Dr Akemi Matsuzawa, Ibaraki Christian University, Japan

As fewer children are born who will ultimately support a rapidly aging society, Japan requires policies supporting informal home carers. In 2010, the local government of Hanamaki City, which is located in Iwate Prefecture in the northern part of the Tohoku area of Japan and has a population of about 100,000, pioneered home visiting by informal carers.

The purpose of the program was to alleviate the anxiety and other problems encountered daily by such carers. The targets of the program were informal carers of subjects with recognized long-term care needs but who non-service use of long-term care insurance. Three non-healthcare professional home visitors listened to and advised the informal carers.

The objective of our present study was to evaluate the effectiveness of support provided by the local government of Hanamaki City to informal home carers of homebound elderly subjects. We used thematic qualitative analysis to explore data gathered over three years of home visits. The data were extracted from case notes written by home visitors between 2011 and 2015.

Annually, 693–869 informal carers with elderly subjects were visited by home visiting workers enrolled in the program. The visiting workers reported the program reduced the stress and burdens they experienced, made them feel less isolated, improved the access of those visited to day and short-stay healthcare services, and improved the family relationships of those visited.

The home visiting program improved the outcomes of informal home carers. The outreach service was thus effective. The program reduced the stresses and burdens encountered by informal carers and either prevented or afforded early identification of abuse and neglect by family members of those visited. However, few local governments conduct programs supporting informal home visitors; the Hanamaki program was pioneering in nature. In Japan, informal carers receive very little assistance. Given the critical roles played by such carers, Japan-wide support systems are essential. This study was supported by JSPS, KAKENHI-C 26502614.

Hearts In Mind Project

Presenters and authors: Georgina Mills and Lisa Petersen, Hearts In Mind Victoria

Hearts in Mind Victoria is a not for profit community organisation working with women who care for a family member with autism, disability or other long term additional needs, to look after their own wellbeing.

As this new era of care unfolds in our changing world, Hearts in Mind creates unique and innovative programs to engage carers to explore ways to take time for themselves and rejuvenate. We offer focused carers programs directed at this specific segment of the carer community that is heavily impacted by a long term caring role.

Research shows that carers in this category have increased levels of anxiety, stress, social isolation, risk of family breakdown and family violence from adult children and reduced employment opportunities, and our own current evaluation data indicates the same.

Hearts in Mind runs two weekly programs based on an early intervention model.

Mindful Art Project is a series of creative workshops using a holistic approach. Participants are motivated to take a daily photograph as a reminder to take a 'mindful moment', culminating in a collective exhibition, encouraging the wider community to see and take notice.

Mindful Wellbeing for Carers is a nine week group therapy based program, delivered by a psychologist and Carers Counsellor to address anxiety, stress and social isolation.

Evaluation of our project in 2016 resulted in positive evidence based outcomes as below:
Carer Outcome Statements

The relationship between filial piety and caregiver burdens in Taiwan: Experiences from family caregivers with care recipients in long term care facilities

Presenter: Professor Tsuann Kuo, Chung Shan Medical University, Taiwan

Family caregivers in modern Taiwan often face the challenge trying to balance between caregiver responsibilities and caregiver duties based on the belief of filial piety. When family caregivers face care needs, the decision to place an older loved one into institutionalized care can result in guilt, regret, family disgrace, or being looked down upon by others. The purpose of this research was to explore the relationship among filial piety, caregiver stress and caregiver burdens. Using a mixed method study design, a structural questionnaire and qualitative interviews were administered. As a result, a total of 281 surveys (with 98% return rate) and six transcribed interviews were analysed.

The results showed the average age of respondents was 53.1 years. The majority of respondents were women (61.3%) with college degrees, and usually daughters (47.8%) and sons (35.4%). Based on these demographic findings, most respondents were daughters with full time work, which was different from traditional caregivers of daughters-in-law. From the results, it seems the daughters still have responsibilities of taking care of their parents in the modern society.

The quantitative analysis also found a statistically significant relationship among filial piety, caregiver stress and caregiver burdens. It showed that filial piety ($p < 0.05$), caregiver stress ($p < 0.001$), small family size ($p < 0.05$), Buddhist ($p < 0.05$) and high frequency of visits had a positive correlation with caregiver burdens. From the qualitative data, respondents had different explanations about filial piety because caregiver stress depended on different caregiving situations, which impacted caregiver burdens. However, caregiver burdens seemed most intensive when filial piety was used as a benchmark to measure as a good virtue.

To conclude, as the society continues to age fast and the care options become diverse, policies need to be more flexible for caregivers to combat different caregiving situations. As for service providers, understanding family caregivers and their beliefs more in depth should be assessed in order to reduce their caregiving stress and caregiver burdens.