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The nutrition and food-related roles, experiences and support needs of female family carers of malnourished older rehabilitation patients

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Abstract

Background: In order to improve perceived value of nutrition support and patient outcomes, the purpose of this study was to determine the nutrition and food-related roles, experiences and support needs of female family carers of community-dwelling malnourished older adults admitted to rehabilitation units in rural NSW, Australia, both during admission and following discharge.

Methodology: Four female family carers of malnourished rehabilitation patients aged ≥65 years were interviewed during their care-recipients' rehabilitation admission and two weeks post-discharge. The semi-structured interviews were audiotaped, transcribed and analysed reflecting an interpretative phenomenological approach by three researchers. A series of "drivers" relevant to the research question were agreed upon and discussed.

Results: Three drivers were identified. "Responsibility" was related to the agency who assumed responsibility for providing nutrition support and understanding family carer obligation to provide nutrition support. "Family carer nutrition ethos" was related to how carer nutrition beliefs, knowledge and values impacted the nutrition support they provided, the high self-efficacy of family carers and an incongruence with an evidence-based approach for treating malnutrition. "Quality of life" was related to the carers' focus upon quality of life as a nutrition strategy and outcome for their care-recipients, and how nutrition support impacted upon carer burden.

Principal conclusions: Rehabilitation units and rehabilitation dietitians should recognise and support family carers of malnourished patients, which may ultimately lead to improved perceived benefit of care and patient outcomes. Intervention research is required in order to make strong recommendations for practice.

Introduction

Enhancing the effectiveness of nutritional care to improve the overall health of older adults will be key in reducing hospital and aged care facility demand, a priority target of current health service research and policy [1-3]. Protein-energy malnutrition (herein referred to as 'malnutrition') is an expensive consequence and cause of disease and presents a significant burden to rehabilitation facilities, where approximately 14–65% of all older adults are malnourished worldwide [4-8]. Furthermore, a recent study found that malnourished patients admitted to rural rehabilitation units were likely to be discharged with malnutrition and remain moderately malnourished for at least three months in their homes [9]. Significantly, although all patients in this study had family carers (herein referred to as 'carers'), these carers were not engaged by the rehabilitation nutrition support services [9].

There is good evidence that malnutrition-related interventions delivered to carers are able to improve or prevent decline in nutritional and functional status and quality of life, without increasing carer burden [10]. The engagement of carers as part of the nutrition care team in rehabilitation presents a unique opportunity to improve nutrition care and outcomes, as the intervention is centered on the needs and preferences of patients and their family members or friends who provide the majority of their care. The rehabilitation setting is ideal for such interventions as the longer length of stay increases opportunities to engage carers. Importantly, involving the carers supports the primary purpose of rehabilitation, which is to facilitate successful transitioning back to the community or residential aged care.

Exploring the nutrition and food-related roles, experiences and needs of carers of malnourished older adults, both during and following the rehabilitation admission, could ensure the development of intervention strategies that are both patient-and carer-centred. Therefore, in order to inform the design and delivery of future nutrition support interventions

for older rehabilitation patients and their carers, a qualitative exploration was undertaken to understand this phenomenon in the interpretive paradigm.

Research question

What are the nutrition and food-related roles, experiences and support needs of female family carers of community-dwelling malnourished older adults admitted to rehabilitation units in rural New South Wales (NSW), Australia, both during admission and following discharge?

Methods

Study design

This longitudinal qualitative investigation was implemented as part of the Malnutrition in the Rural Rehabilitation Community (MARRC) study. Semi-structured interviews were conducted at two time-points to understand the carer roles, experience and support needs during and after the rehabilitation stay, with analysis guided by interpretative phenomenological analysis (IPA). This approach was selected as the research was focussed on interpreting the lived experience of carers to inform future interventions to improve health service delivery [11-13].

Participants and setting

Participants were sampled from two public, general rehabilitation units (24 and 31 beds) in the same local health district in rural NSW, chosen by convenience based on location. Participants were eligible if they were English-speaking female family carers aged ≥18 years, and cared for a community-dwelling inpatient aged ≥65 years with malnutrition (determined by the rehabilitation dietitian). In order to produce a homogenous sample, female carers were chosen as they represent the majority of family carers [14]; however, reflecting the IPA approach, a "representative" sample was not sought. For this study, a family carer was considered to be a family member or close friend who either lived with the older adult or did

not live with the older adult but provided assistance with activities of daily living, with point-of-contact ≥4 days per week. Carers were identified from medical records and the older adult inpatient. Exclusion criteria for carers were: history of abusive or threatening behaviour; unsafe dwelling or a dwelling located ≥1.5 hours' drive from the rehabilitation facility as per medical records.

Carers were identified through purposive sampling facilitated by the rehabilitation dietitian (independent of the research team) and the primary researcher (SM): all patients identified as at risk of malnutrition (via the Malnutrition Screening Tool [15]) were referred to the rehabilitation dietitian for full nutritional assessment. With permission from the patient, potentially eligible carers were approached by the researcher to invite them to participate. Reflecting the IPA approach [16, 17],[18], a small sample size of four participants (two daughters and two spouses) was considered appropriate for the current study.

The usual care for care-recipients was individualised medical nutrition therapy from the rehabilitation dietitian (0.15 full time equivalent per rehabilitation unit). Involvement of the carer occurred opportunistically at the discretion of the carer and the rehabilitation dietitian. Usual post-discharge nutrition support may involve referral to publically-funded dietitian outpatient clinics and/or prescription of subsidised oral nutrition supplements. The researchers were not involved in the care of the care-recipients and provided no intervention.

Ethical considerations

Ethical and governance approvals were obtained as part of the MARRC Study (North Coast Human Research Ethics Committee approval number LNR 063, G108). Written informed consent was obtained from all carer participants. A small travel reimbursement (AU$15) was offered to participants to cover transport costs; however two participants refused

reimbursement. A waiver of consent was granted for the collection of basic demographic data from the rehabilitation inpatients (care-recipients).

Interviews

Care-recipients did not attend interviews. The primary researcher conducted face-to-face semi-structured interviews with carers at two time points (T1 and T2):

T1) During the care-recipients' admission (at least 7 days post-admission) in a private room at the rehabilitation unit.

T2) Two weeks post-discharge in a private room at the carers' home, workplace or at the rehabilitation unit.

The first carer interview was also a pilot, used to create the interview schedules (Online Supplementary Material 1 and 2) and trial the analysis. The primary researcher collected demographic data about the carer and their care-recipient via interview and medical records. During the interviews, the primary researcher maintained a journal of field observations and thoughts/impressions to aid data analysis.

Data analysis

Interviews were audio-recorded and transcribed verbatim by SM. Identifying information was removed from the transcripts. Codes were developed using qualitative analysis software (NVivo for Windows, Version 10. QSR International Pty Ltd, Australia). Thematic analysis was guided by the IPA method described by Smith et al. [17] and Phillips et al. [16, 19]. Specifically:

1. Individual interview transcripts were studied independently and on multiple occasions by SM. Line by line coding was used, and potential themes (words or short phrases) developed for each interview, including contradictory extracts within a particular

theme. A secondary researcher (EI) reviewed transcripts and codes; additional codes were produced and existing codes expanded.

2. Potential themes were discussed and compared by SM and EI until consensus resulted and a long list of themes created for each interview.
3. Themes with commonality were grouped into “higher themes” for each interview. Divergences and convergences between linked interviews (T1 and T2 by the same participant) were particularly considered when developing higher themes.
4. The nutrition and food-related significance of the higher themes were considered; those considered to be unrelated to food and nutrition or not relevant to the research question were excluded. Examples were the higher themes of medical status and non-food-related social interaction. Higher themes and their relevance were assessed by SM and confirmed with EI.
5. Both researchers compared the higher themes across all interviews at each time-point (T1 and T2), producing “shared themes” that reflected commonalities across all interviews and time-points and the field notes of the primary researcher.
6. Commonalities in shared themes were identified which allowed them to be further grouped into “super themes”, also known as “drivers”.
7. From the literature, a relevant theoretical framework was selected to explain and interpret the drivers.
8. The drivers and theoretical framework were used to describe and interpret the experience of carers during their care-recipient’s rehabilitation admission and post-discharge, and make suggestions for practice.

An electronic and paper-based audit trail was reviewed by a third, independent researcher (DR). Any disagreements or contested themes were discussed between the three researchers until consensus was reached. Final, agreed drivers encompassed themes occurring across

most accounts and which best answered the research question. Findings were integrated with the discussion to support synthesis for the reader [20].

Findings and discussion

Four female participants were recruited from one rehabilitation unit only (Table 1). Interviews were conducted from July 2015 to January 2016, and all participants attended both interviews (T1 and T2). Each interview was conducted alone with the carer, with the exception of one interview (T1; Joan), which was also attended by Joan's neighbour Vicky (pseudonym used) at the request of Joan. Vicky provided informed consent to participate in the study; however, her contribution was minimal. The T1 interviews were conducted from 11 – 28 days following admission and were 25 – 36 minutes duration, and the T2 interviews were conducted 12 – 21 days following the care-recipients discharge from rehabilitation and were 6 – 15 minutes. The T2 interviews were shorter than expected as carers' experiences and needs had not significantly changed since T1.

Three interrelated drivers were identified, each with a further two sub-themes (Figure 1). The drivers and sub-themes were consistent with a theoretical framework (herein referred to as the family caring & health-related outcomes framework) which provides theoretical background for relevant findings [21]. The framework proposes four domains that address the effects of family carers on the health-related outcomes of older adult care-recipients in home health care: type of carer (spouse, offspring, relative, non-relative); nature of caregiving relationship (availability, familiarity, motivation, care recipient's preference, burden); type of caregiving (psychosocial vs direct care); and internal processes of the care recipient (psychological, behavioural and physiological processes). These domains are informed by task-specific theory, hierarchical-compensatory theory, burden theory, direct effect theories, and stress-related theories [21].

Driver: Responsibility

Agency responsible for providing nutrition support

The researchers considered three candidates who may assume responsibility for providing nutrition support for malnourished older rehabilitation patients: carers, the health service (including rehabilitation dietitian) and the care-recipients.

The high responsibility experienced by the carer in providing nutrition support to the care-recipient was strongly expressed across all interviews. The carers saw nutrition support as one of their key roles, which continued during the rehabilitation admission.

> *"… we had a picnic the other day outside, and we had salmon rolls, and a banana, no, fruit salad I made him. So when I come I bring something, just to boost what he's getting at present" (T1, Jill, carer for Lester).*

This finding illustrates the importance of the nature of the caregiving relationship and the motivation of the carer to provide physical and psychosocial care [21], aligning with the concept that older adults may experience less psychological consequences when care is provided by their preferred person, such as a familiar family carer [21, 22]. Interestingly, all carers, at both time-points, recognised that nutrition or eating was a difficulty or problem for their care-recipient, but failed to seek formal nutrition support. Although there were multiple reasons why the carers did not seek formal nutrition support in the current study (Table 2), all carers expressed a strong desire to be highly involved in any form of nutrition support that the health service provided to their care-recipient.

> *"I think it's awfully important to be involved, particularly if he's coming home. I'd have to be. That's, you know, that's the be all and end all of that. I mean, I'd have to be… I'm buying the food, I'm cooking the food, I'm serving the food… I must be involved in that" (T1, Joan, carer of Alfred).*

It was further interpreted that some carers expected that the health service had a responsibility to provide information to the carers about nutrition support services, and likewise the rehabilitation dietitian should have actively sought out and engaged with the carer whenever care was provided to a malnourished patient. Similar studies have found that whilst carers of older adults may receive praise for their caregiving, they are given little practical assistance by health care providers [24, 26-29]. Thus, although previous theory has described formal support as the final preference of elderly care-recipients (coming after care provided by family members) [22], it was clear in the current study that carers themselves perceive such formal support as essential to performing their own role as family carers. Carers further expressed that, in their experience, their contribution in providing nutrition support was not recognised by the health service. A model of care focussed only on the partnership between the health professional and the patient may ignore the overlap between professional and family carers, particularly considering that family carers assume primary responsibility for the care-recipient's overall wellbeing [23].

Finally, carers experienced that the care-recipient themselves assumed low responsibility for their own nutritional status and dietary intake.

> *"Mum's always been very aware of nutrition, so it's been hard to see her like this, in a state that she's not really… taking care of what she needs" (T1, Amanda, carer of Velma).*

> *"He wouldn't listen [to nutritional advice]" (T1, Joan, carer of Alfred)*

Amanda's quote represents Velma as undergoing a change in her interest and value in nutrition, and that her current lack of responsibility for her own nutrition support did not reflect her long-term nutrition values in Amanda's experience. Alternatively, Joan gave her experience of Alfred as having a firm and long-standing disinterest in nutrition advice.

Overall, all carers' experiences were that their malnourished care-recipients assumed low responsibility for their own nutrition, irrespective of the reason, and this is important in understanding why some care-recipients may have poor adherence to nutrition interventions. In addition, the perceived low responsibility assumed by care-recipients was interpreted to impact upon the carers' assumed responsibility for providing nutrition support. Internal processes of a care-recipient, incorporating self-esteem, meaning of life, obligation to life, loneliness and stress have been linked to health care adherence [21] and may provide some insight into the reasons why the care-recipients in the current study were perceived to assume little or no responsibility by their carers.

Family carer obligation

> *"I find it very hard. I find it very constant. I find him extremely unappreciative. He's eating very well now, good meals, because I'm trying to build him up, because he's going in for the operation to get a TURP [crying]. And he needs to be as strong as he can be… so I'm doing all I can from my side to strengthen him" (T2, Jill, carer of Lester)*

This quote exemplifies? our interpretation of how the carers' provision of nutrition support was linked to their experience of the care-recipient taking little responsibility, and how this was linked to carer burden (Figure 1). But further than that, we interpreted that Jill's provision of nutrition support was voluntary in some ways (due to the emotional connection with Lester) and involuntary in other ways (due to Lester placing high demands for care on his wife). As discussed earlier, all carers experienced feelings of obligation to provide nutrition support for their care-recipients, but the motivation behind this obligation was diverse, including varying degrees in which this responsibility was voluntarily assumed by the carer. Some carers seemed to naturally assume the responsibility for providing nutrition support on their own volition, whereas others felt this role was involuntarily placed upon

them. As the quote by Jill illustrates, the emotion that she expressed revealed how she was personally invested in the wellbeing of Lester. Both Jill and Amanda expressed that, at least partially, they provided their nutrition support out of their feelings of both emotional and self-interested obligation. Because the continued wellbeing of their care-recipients was important to them emotionally, their caregiving was expressed to be more self-initiated and voluntary. Conversely, Cindy expressed her obligation to provide care due to societal and/or legal pressures.

> *"[if we didn't provide care]…and you know it looks like we're not doing the right thing by her" (T2, Cindy, carer of Leona).*

When initially contacted, Cindy was concerned of negative repercussions if the researcher felt her care was inadequate. In this case, the researcher perceived there was less emotional connection to the care-recipient than the other carers, as Cindy had only known Leona for two years, and her husband (Leona's son) did not have a close relationship with Leona. For Cindy, we interpreted that the provision of care seemed less voluntary than for Amanda and Jill. These findings can be further interpreted by examining the nature of the caregiving relationship, given that the motivations for caregiving may be different depending on the type of carer, such as spouse, offspring or non-relative [21].

Joan did not see herself as a carer, instead stating that her role as a wife had not changed with Alfred's worsening health status. However, Joan had significant support needs herself, which may have contributed to why she did not recognise her caregiving role. Alternatively, Joan may see caregiving as an extension of her spousal relationship, previously proposed to occur as a consequence of wider sociocultural roles [21, 32].

Previous researchers have proposed that spouse carers experience less role strain than daughters, who have a greater burden due to a reversal of roles [21, 30, 31]. However, despite the

varying origins of carer obligation, all carers expressed their willingness to assume the responsibility for nutrition support. Obligation perceived by the carers was interpreted to differ depending on influences from the other drivers. For example, when providing nutrition support was perceived to have a negative impact on the carers' own quality of life (Figure 1), the less voluntarily, or with a less emotional and self-interested sense of obligation, the care provision seemed. Conversely, other carers tended to be more willing to assume the responsibility, especially if they held a strong nutrition ethos (Figure 1). Aligning strongly with the family caring and health-related outcomes framework [21], quality of the personal relationship between the carer and the care-recipient was identified as a major influence affecting the willingness to provide care, closely aligned with the emotional sense of obligation.

> *"I've discovered how very much I miss him when he's been away. He's a very big part of my life, and we've been married for 60 years…It is very important to me that he does as well as he can for as long as he can… And him being well fed, and getting strong is a very important part of that, you know" (T1, Jill, carer of Lester).*

> *"She doesn't want to be pushed. Um, as I said, she's a very stubborn lady, but the thing is always "*no, whatever you want*" (T1, Cindy, carer of Leona).*

<u>Family carer nutrition ethos</u>

Family carer nutrition ethos captures the effect of the nutritional values, beliefs and knowledge of the carers on their persistency and the type of nutrition support strategies they used. Across the interviews, it was observed that the more value the carer placed on nutrition (or a particular nutritional belief), the more persistent, voluntary or proactive they were with the provision of their nutrition support. The type of nutritional belief, and how strongly it was valued, in turn affected the nutritional priorities and strategies employed by the carer.

"It [nutrition] would have to be one of the most important things to me, for me, at this time with my son as well, yeah, very important… I do tend to keep our diet as restrictive of as much dairy as I can, as much wheat as I can, and I've just recently become vegetarian and on my way to becoming vegan… [later in the interview]…so I would like mum to eat kind of more fruit and vegies, you know but she's not going to, so, there's not really.. There's kind of like a bit of a wall with mum" (T1, Amanda, carer of Velma).

However, those who did not hold specific nutritional beliefs or value nutrition as strongly as others saw nutrition support as just another task included as part of their caregiving, and opted for a simple strategy of food provision rather than any particular dietary approach.

"Well as far as value [of nutrition] is concerned, I wouldn't put anything. You get up, you prepare breakfast, you have something to eat if you're hungry, you know. I always have plenty of vegetables and stuff" (T1, Joan, carer of Alfred).

"Well, no, he's eating just the same [as prior to fall and rehabilitation admission]. And I don't know whether it's perhaps lack of exercise, you know, that's making him weak. You see he's not exercising, he's not walking… mainly because he can't" (T2, Joan, carer of Alfred).

This second quote by Joan was interpreted to reflect that she attributed Alfred's condition to exercise as opposed to dietary intake or nutrition, and did not appear to be highly motivated to provide additional nutrition support despite his continuing malnutrition. However, there may be other reasons Joan was not particularly focused on nutrition support, such as the lack of responsibility and obstinacy against nutrition intervention that Alfred that she had earlier characterised in him.

Family carer self-efficacy

There was a strong impression that all carers felt the nutrition support strategies they provided were sufficient and effective, and that their current level of nutrition knowledge was adequate. This was a contributing factor to the lack of engagement with formal services such as the rehabilitation dietitian (Table 2). However, there was a divergence in self-efficacy in providing nutrition support overall; specifically for time availability and receptivity of the care-recipient. The two younger generation carers (daughter and daughter-in-law) expressed time and/or distance constraints limited their ability to provide nutrition support; and two carers (daughter-in-law and wife) expressed intransigence of their care-recipients as a limitation. Understanding this finding may be enhanced in the context of the nature of the caregiving relationship which includes availability as a key determinant [21].

> *"…I worry about her, and worry about finding the time to come up and do a shop with her…" (T1, Amanda, carer of Velma).*

> "*It's alright for me to go through all these, umm, sort of suggestions, but it's another thing getting him to follow it. He is a very, very determined man. He will not do anything he does not want to do" (T2, Joan, carer of Alfred)*

Nutrition support strategies used by carers were all highly individualised to cater specifically for their care-recipient's food preferences, lifestyle and culture.

> *"…when I did do the, looked at the Polish, um, history…And I thought "*wow, that's really different*", here we are trying to introduce a certain type of food to people, and eat breakfast lunch and dinner, they, they don't do that. And I thought, oh, that's really interesting, this is probably why she eats when she wants to eat, because yeah there's no set times…" (Edited text, T1, Cindy, carer of Leona).*

The individualised approach used by carers may have led to a high success rate in their provision of nutrition support, in turn contributing to the carers' self-efficacy, and subsequent concern over the quality of formal support (Table 2). The family caring and health-related outcomes framework [21] supports this finding, where familiarity is shown to impact upon health outcomes through alignment of understanding and lifestyle between the carer and care-recipient. The high self-efficacy of carers facilitated through familiarity may also link with the high responsibility assumed by carers for providing nutrition support discussed earlier.

Incongruence with evidence-based approach

Amanda's description of her restrictive diet (quoted earlier) demonstrated her strong nutritional belief in the importance of "whole foods", fruits and vegetables. Although Amanda attached strong values to these foods, all carers believed that a healthy diet with plenty of vegetables was the most important nutritional strategy. This promotion of fruit and vegetables (low-energy and vitamin/mineral-rich foods), whilst a recognised theme, was less important to the researchers in the analysis than the significance of how this approach does not align with the evidence-based approach for treating malnutrition by promoting energy- and protein-rich foods and beverages [33].

Similarly, of importance to our interpretation within this sub-theme, there was limited discussion about protein during the carer interviews. Jill had the strongest focus on protein, as Lester and Jill had seen a dietitian in acute care where the importance of protein intake was discussed. However, even where the carers recognised the importance of protein, their nutritional knowledge and nutrition support strategies remained inadequate.

> *"Ah, well, when you asked me "would a dietitian help me", I thought I knew it all. And further to our discussion I realise that the way I see healthy eating, and the way that Lester needs healthy eating to put on weight, are reversed!" (T2, Jill, carer of Lester).*

Quality of life

Focus on care-recipient quality of life

Although the nutrition support strategies described by the carers tended to focus on fruit, vegetables and healthy eating, it was interpreted that the reason behind this was strongly related to quality of life. Carers revealed that their purpose in providing nutrition support was to improve the care-recipients' overall quality of life, rather than nutritional or medical outcomes.

> *"If she starts to enjoy life a little bit more, and starts to enjoy this phase of her life, and enjoy her eating…its part of life isn't it? Not wanting to eat and actually be amongst it and involved…it's just such a beautiful thing, so, food is such a beautiful thing, so it would be lovely to see her enjoying that" (T1, Amanda, carer of Velma).*

The carers also frequently described non-nutrient-related nutrition support strategies which were directly aimed at improving quality of life.

> *"Try and make the meal time a happy time, and, umm, perhaps add a glass of port! [Laughs] To make it…as pleasant time as you can, because I think that does help the appetite" (T2, Jill, carer of Lester).*

Therefore, the care-recipients' quality of life was seen as both a strategy and an outcome in nutrition support, overall suggesting that nutrition support was approached holistically with a focus upon quality rather than physical outcomes. Literature has shown that carers frequently provide both psychosocial support as well as direct health-related care [21], with a carer's influence on a care-recipient's health encouraged through psychosocial processes such as promoting positive obligation to life and reduced stress [21].

Family carer burden

The carers' own quality of life was important and diverse, both between carers and within the same carer over time.

> *"So you know, he's not selfish in that way, he's keen for me to have a life as well. Cause you've got to have a life as well, you know…Even though it might be a tiny bit restricted, it's still a life" (T1, Jill, carer of Lester).*

> *"I find it very hard, very constant…I find him very unappreciative" (T2, Jill, carer of Lester).*

Jill conveyed that burden of care significantly increased following Lester's discharge from rehabilitation. However, this was not the case for all carers. Joan did not report increased burden of care; however, she did require significant additional domiciliary and health care support. Amanda did not have the time to visit and assist Velma following her discharge from rehabilitation, but this increased her anxiety regarding her mother as she desired to be able to provide more care. Cindy reported a significant increase in quality of life following Leona's discharge from rehabilitation; however, unlike the other care-recipients, Leona was not discharged home as originally planned, but instead discharged to a residential aged care facility.

> *"Exactly, and this is why like carers end up themselves becoming very sick…this is why really the carers need looking after in their nutritional… you know, not just nutrition but just being able to have that respite, that care… [later in interview]...I've got freedom now!...I don't have to worry" (T2, Cindy, carer of Leona).*

Educating family carers of malnourished older adults has been previously shown to improve patient outcomes but have no effect on carer burden [10]. The current study provides insight on why this may be the case; as all carers were already assuming the responsibility for nutrition

404 support and wanted to be involved in any formal nutrition support provided to their care-
405 recipient. However, this does not imply that the carer burden is low, as there is good research
406 showing that carers of frail or malnourished older adults have a significant burden of care
407 leading to a lower quality of life [34-36].

408 Implications for research and practice

409 Broadly, the findings of this study challenge current practice with the nutrition and dietetic
410 care process [37, 38] . It suggests that the way care is delivered in rehabilitation facilities for
411 older malnourished patients should change through the integration of formal and family
412 nutrition support, across both the wider rehabilitation unit and dietetic services. The
413 suggestions for practice described here have been specifically linked to the study findings in
414 the Online Supplementary Material 3.

415 Within rehabilitation units, system changes are required to ensure family carers are aware of
416 the nutrition support resources available to them, and are assisted to access these services.
417 Specifically for dietetic practice, dietitians should identify and deliberately engage family
418 carers of malnourished patients and recognise that the care-recipient themselves may assume
419 less responsibility for their nutritional intake than the carers. Additionally, dietitians should
420 understand carer nutritional beliefs and the types of nutrition support strategies used by the
421 carer, as well as the motivations behind them, in order to make more carer-centred
422 recommendations and correct inappropriate nutrition strategies. Such strategies should still
423 acknowledge the cultural background and food preferences of their patients, in order to
424 provide individualised medical nutrition therapy. In developing strategies, an understanding
425 of the current caregiving concerns of the family carer and joint problem solving is required,
426 so that strategies can be needs-based and provide a meaningful contribution to the pre-
427 existing family carer–care-recipient partnership. Finally, dietitians should recognise that
428 family carers may focus their care upon improving the quality of life of their care-recipients

rather than improving nutritional or clinical outcomes. This focus on quality of life should be incorporated in strategies to improve their acceptability to the family carer. Whilst these suggestions may improve practice, further research and evidence is required to develop the evidence base. In order to support the transition of these suggestions to evidence-based recommendations, intervention studies are needed to determine if the proposed coordination of efforts of the rehabilitation dietitian, the carer and the patient will increase the efficacy of nutrition support. The findings of this study suggest that such research should consider not only patient outcomes, but also outcomes in the carer. Finally, further qualitative studies should explore the experiences of male carers of malnourished older adults in rehabilitation, as well as carers in other settings, to better improve understanding.

Limitations

The interviews by the four participants in this study offered rich and diverse themes for exploration and analysis by the researchers; however, the unexpected shorter length of interviews, particularly T2, and lack of data on the severity of malnutrition of the care-recipient are limitations. In addition, due to the purpose of the study, only those themes which were related to the research question were pursued.

Finally, as with all qualitative research there is potential for bias as a result of the researchers' professional, clinical and personal backgrounds, all of whom were Accredited Practising Dietitians. Reflexivity was used throughout the analysis process and in reporting the results in this manuscript to acknowledge this.

Conclusion

"Responsibility", "family carer nutrition ethos", and "quality of life" were identified as three drivers of female family carers of malnourished older rehabilitation patients. Rehabilitation units and rehabilitation dietitians should recognise and support family carers of malnourished

patients during and after the patients' rehabilitation admission, which may lead to improved patient outcomes and perceived benefit of care. Interventional research is required in order to make strong recommendations for practice.

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Transparency Declaration

The lead author affirms that this manuscript is an honest, accurate, and transparent account of the study being reported, that no important aspects of the study have been omitted and that any discrepancies from the study as planned (and registered with) have been explained. The reporting of this work is compliant with RATs[39] guidelines.

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Table 1: Demographics of the female family carers and their malnourished care-recipients

Demographic	Amanda*	Jill*	Cindy*	Joan*
Family carer demographics				
Age	45 years	84 years	59 years	85 years
Relationship to care-recipient	Daughter	Wife	Daughter-in-law	Wife
Highest level of education	Trade	Tertiary	Tertiary	Secondary
Marital status	Divorced/ separated	Married	Married	Married
Country of birth	Australia	Australia	Australia	England
English as first language	Yes	Yes	Yes	Yes
Ethnicity	Caucasian	Caucasian	Caucasian	Caucasian
Religion	No religion	Christianity	Christianity	No religion
Currently dieting	No	No	No	No
Pension	Single parent	Aged	None	Aged
Living with care-recipient	No	Yes	No	Yes
Assist care-recipient with grocery shopping	Yes	Yes	Yes	Yes
Assist care-recipient with food preparation	No	Yes	Yes	Yes
Care-recipient demographics				
Care-recipient*	Velma	Lester	Leona	Alfred
Care-recipient length of rehabilitation stay	36 days	42 days	35 days	32 days
Care-recipient age group	65 – 69 years	85 – 89 years	85 – 89 years	85 – 89 years
Care-recipient gender	Female	Male	Female	Male
Care-recipient discharge location	Home	Home	Residential aged care facility	Home

*Pseudonyms used.

Table 2: Family carers' reasons for not engaging with formal nutrition support provided by the rehabilitation unit during or after their care-recipients' rehabilitation admission.

Reason	Quote	Details*
Lack of knowledge of any nutrition support services	*"Not really aware of any [nutrition services in rehabilitation], apart from, you know, just… I wasn't really aware of any of them"*	T1, Amanda, carer of Velma
Belief that if help was needed then the health service would take initiative to intervene and engage the caregiver	*"Probably because I don't know enough about a nutritionist, how they would work, it would be something that the hospital would have to talk to us about, or the hospital would refer the nutritionist to us"*	T2, Cindy, carer of Leona
Belief the rehabilitation nutrition support services are unable to assist their care-recipient due to inadequate knowledge of the individual	*"She eats a lot of fish… they haven't been feeding her fish, and that's all she mainly eats… That is one of the main reasons she's not eating here"*	T1, Cindy, carer of Leona
Belief that they have enough knowledge and resources to provide sufficient nutrition support without assistance from formal services	*"I sort of feel I understand what's needed… unless I had a problem… when you asked me "would a dietitian help me", I thought I knew it all"*	T2, Jill, carer of Lester
Concern over the cost of formal nutrition support services	*"But all you think of is "hang on, if I'm going to get a nutritionist, it's going to cost me an arm and a leg"*	T2, Cindy, carer of Leona
Failure to recognise malnutrition and need for a specialised dietary approach	*"Quite shocked actually [at learning Alfred has malnutrition". I mean, ah, I suppose he is thin, but I have never known him any other way. I can't say I've looked at Alfred over the last few months even and thought you know, you look thinner than…"*	T1, Joan, carer of Alfred

*Pseudonyms used.

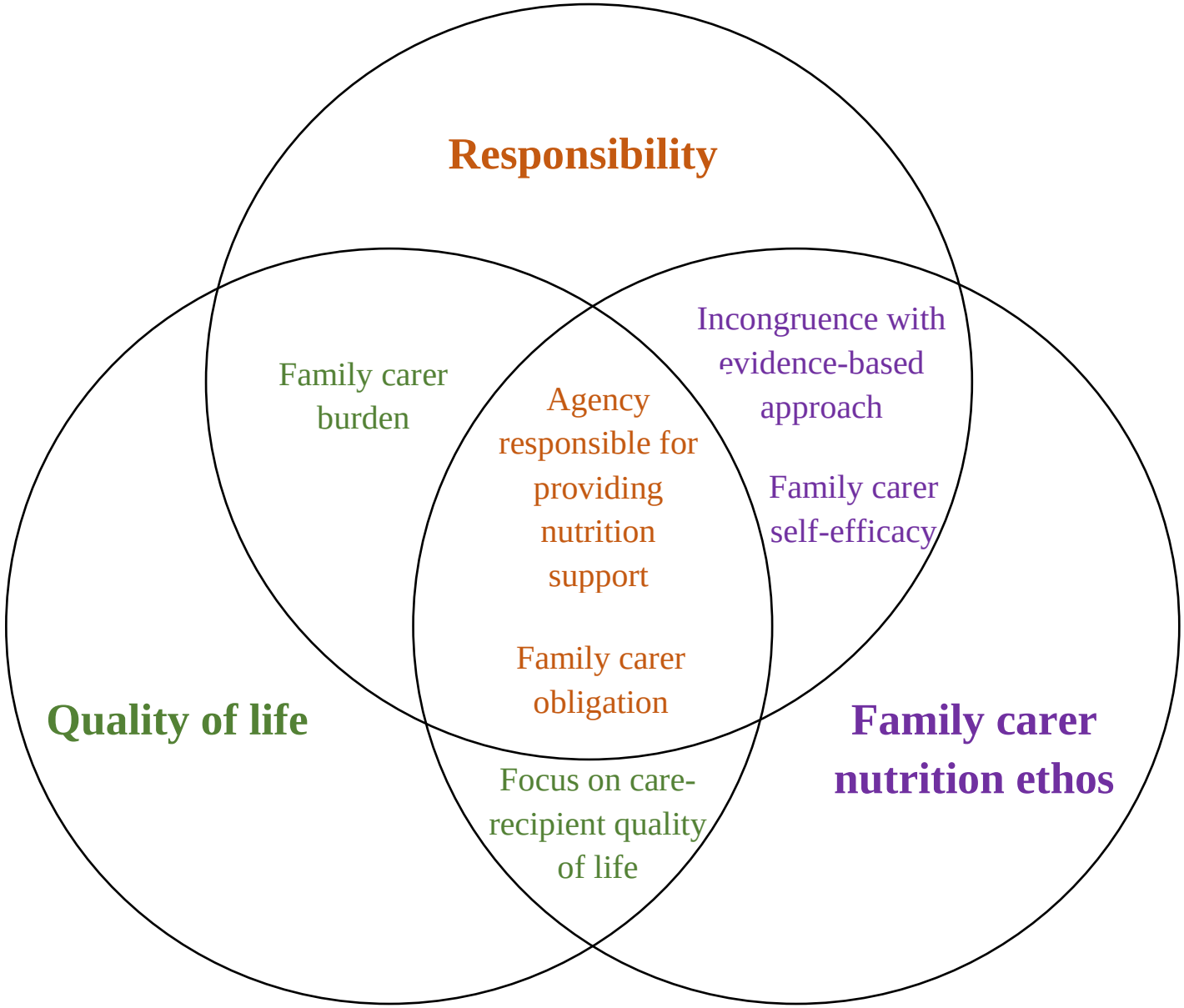

Figure 1: Schematic overview of three interconnected "drivers" and their sub-themes which represent the nutrition and food-related roles, experiences and support needs of female family carers of malnourished older rehabilitation patients.

Online Supplementary Material 1: The MARRC Study interview schedule during rehabilitation (T1)

Values, beliefs and knowledge of caregiver	• What value do you place on nutrition in your own health? • What comes to mind when you hear the word "malnutrition" • What is the biggest food related concern you have for your friend/relative/spouse currently? • What experience have you had with dietitians? • What experience have you had with nutrition supplements? • What tips or advice would you share with someone in a similar situation as you to help support the nutrition of your friend/relative/ spouse?
Experience of caregiver at home	• How do you feel about your role as a caregiver in general? • What has been your experience in providing or preparing food for your friend/relative/ spouse prior to their current stay in rehabilitation? • How do you think your role as a caregiver will change when your friend/relative/ spouse is discharged home? • Once your friend/relative/ spouse is discharged home, what support would you like to receive from dietitians? • What method of contact would you prefer a dietitian uses to support you once your friend/relative/spouse is discharge home?
Experience of caregiver in rehabilitation	• What are the nutrition services you know exist in rehabilitation? • What value do you place on nutrition to support your friend/relative/ spouse through their current stay in rehabilitation? • How involved would you like to be in the nutrition support of your friend/relative/ spouse during their stay in rehabilitation? • How do you feel about your friend/relative/ spouse's diagnosis of malnutrition? • What help or support do you want from nutrition services in hospital or rehabilitation?

a The interview schedule served as a guide and was not prescriptive in the order or wording of questions.

Online supplementary material 2: The MARRC Study interview schedule post-rehabilitation (T2)

Reflection of experience of caregiver in rehabilitation	• What value do you place on nutrition for patients in rehabilitation? • What nutrition services or support did you have during your friend/relative/ spouse's rehabilitation stay? • How do you feel about your caring role during your friend/relative/ spouse's rehabilitation stay?
Experience of caregiver following discharge	• How has your role as a caregiver will changed since your friend/relative/ spouse finished rehabilitation? • What is the biggest food related concern you have for your friend/relative/spouse currently? • What has been your experience in providing or preparing food for your friend/relative/ spouse since rehabilitation?
Support needs and preferences of caregiver	• What tips or advice would you share with someone in a similar situation as you to help support the nutrition of your friend/relative/ spouse? • What support, if any, would you like to receive from dietitians now you're your friend/relative/ spouse has been discharged from rehabilitation? • What method of contact would you prefer a dietitian uses to support you once your friend/relative/spouse is discharge home?

a The interview schedule served as a guide and was not prescriptive in the order or wording of questions.

Online supplementary material 3: The MARRC Study findings which support the suggestions for nutrition and dietetics practice in rehabilitations units.

Suggestion for practice	Findings of the drivers and subthemes which support the suggestion for practice
Rehabilitation units should ensure family carers are aware of the nutrition support resources available to them, and have assistance in accessing these services	· "The carers saw nutrition support as one of their key roles, which continued during the rehabilitation admission" (Agency responsible for providing nutrition support) · "All carers expressed a strong desire to be highly involved in any form of nutrition support that the health service provided to their care-recipient" (Agency responsible for providing nutrition support) · "All carers, at both time-points, recognised that nutrition or eating was a difficulty or problem for their care-recipient, but failed to seek formal nutrition support" (Agency responsible for providing nutrition support) · "Family carers' reasons for not engaging with formal nutrition support provided by the rehabilitation unit during or after their care-recipients rehabilitation admission: Lack of knowledge of any nutrition support services; Belief that if help was needed then the health service would take initiative to intervene and engage the caregiver; Concern over the cost of formal nutrition support services" (Table 2, Agency responsible for providing nutrition support) · "It was further interpreted that some carers expected that the health service had a responsibility to provide information to the carers about nutrition support services" (Agency responsible for providing nutrition support) · "Carers further expressed that, in their experience, their contribution in providing nutrition support was not recognised by the health service" (Agency responsible for providing nutrition support)
Dietitians should identify family carers of malnourished patients,	· "The carers saw nutrition support as one of their key roles, which continued during the rehabilitation admission" (Agency responsible for providing nutrition support)

and actively seek out and engage with them	· "All carers expressed a strong desire to be highly involved in any form of nutrition support that the health service provided to their care-recipient" (Agency responsible for providing nutrition support) · "All carers, at both time-points, recognised that nutrition or eating was a difficulty or problem for their care-recipient, but failed to seek formal nutrition support" (Agency responsible for providing nutrition support) · "It was further interpreted that some carers expected that …the rehabilitation dietitian should have actively sought out and engaged with the carer whenever care was provided to a malnourished patient" (Agency responsible for providing nutrition support) · "Carers further expressed that, in their experience, their contribution in providing nutrition support was not recognised by the health service" (Agency responsible for providing nutrition support) · "Family carers' reasons for not engaging with formal nutrition support provided by the rehabilitation unit during or after their care-recipients rehabilitation admission: Lack of knowledge of any nutrition support services; Belief that if help was needed then the health service would take initiative to intervene and engage the caregiver; Failure to recognise malnutrition and need for a specialised dietary approach" (Table 2, Agency responsible for providing nutrition support) · "All carers expressed their willingness to assume the responsibility for nutrition support" (Family carer obligation)
Dietitians should recognise that malnourished patients may assume low responsibility for their own nutrition support, but that their family carers may assume high	· "The high responsibility experienced by the carer in providing nutrition support to the care-recipient was strongly expressed across all interviews" (Agency responsible for providing nutrition support) · "There was a sense that all carers experienced that the care-recipient themselves assumed low responsibility for their own nutritional status and dietary intake" (Agency responsible for providing nutrition support)

responsibility for their care-recipients' nutrition support	· "Some carers seemed to naturally assume the responsibility for providing nutrition support on their own volition, whereas others felt this role was involuntarily placed upon them" (Family carer obligation)
Dietitians should discuss the nutrition ethos of family carers to understand the types of nutrition support strategies used, and the motivations behind them, in order to make more carer-centred recommendations and/or identify and correct inappropriate nutrition strategies	· "Other carers tended to be more willing to assume the responsibility [of providing nutrition support], especially if they held a strong nutrition ethos" (Family carer obligation) · "It was observed that the more value the carer placed on nutrition (or on a particular nutritional belief), the more persistent, voluntary or proactive they were with the provision of their nutrition support. The type of nutritional belief, and how strongly it was valued, in turn affected the nutritional priorities employed by the carer" (Family carer nutrition ethos) · "All carers believed that a healthy diet with plenty of vegetables was the most important nutritional strategy…this approach does not align with the evidence-based approach for treating malnutrition by promoting energy- and protein-rich foods and beverages" (Incongruence with evidence-based approach) · "Even where the carers recognised the importance of protein, their nutritional knowledge and nutrition support strategies remained inadequate" (Incongruence with evidence-based approach)
When arranging nutrition support strategies, dietitians should investigate the current caregiving concerns of the family carer and utilise joint problem solving, so that their strategies can be needs-based and provide a meaningful	· "Nutrition support strategies used by carers were all highly individualised to cater specifically for their care-recipient's food preferences, lifestyle and culture" (Family carer self-efficacy) · "The carers' own quality of life was important and revealed to be diverse" (Family carer burden) · "Family carers' reasons for not engaging with formal nutrition support provided by the rehabilitation unit during or after their care-recipients rehabilitation admission: Belief that they have enough knowledge and resources to provide sufficient nutrition support without assistance from formal services" (Table 2, Agency responsible for providing nutrition support)

contribution to the pre-existing carer–care-recipient partnership	
As per best-practice, dietitians should explore and acknowledge the cultural background and food preferences of their patients, in order to provide individualised medical nutrition therapy	· "Nutrition support strategies used by carers were all highly individualised to cater specifically for their care-recipient's food preferences, lifestyle and culture" (Family carer self-efficacy) · "Family carers' reasons for not engaging with formal nutrition support provided by the rehabilitation unit during or after their care-recipients rehabilitation admission: Belief the rehabilitation nutrition support services are unable to assist their care-recipient due to inadequate knowledge of the individual" (Table 2, Agency responsible for providing nutrition support)
Dietitians should recognise that family carers may focus their care upon improving the quality of life of their care-recipients rather than improving nutritional or clinical outcomes. This focus on quality of life outcomes should be incorporated as strategies and motivations to improve acceptance by the family carer.	· "Carers revealed that their purpose in providing nutrition support was to improve the care-recipients' overall quality of life, rather than nutritional or medical outcomes (Focus on care-recipient quality of life) · The carers also frequently described non-nutrient-related nutrition support strategies which were directly aimed at improving quality of life" (Focus on care-recipient quality of life) · "Family carers' reasons for not engaging with formal nutrition support provided by the rehabilitation unit during or after their care-recipients rehabilitation admission: Failure to recognise malnutrition and need for a specialised dietary approach" (Table 2, Agency responsible for providing nutrition support)