Title page

Title: Exploring the community pharmacist's role in palliative care: Focusing on the person not just the prescription

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Abstract

Objectives

Changes in health care provision have led to an emphasis on providing end of life care within the home. Community pharmacists are well positioned to provide services to community-based palliative care patients and carers.

Methods

A multiple qualitative case study design was adopted. A total of 16 focus groups and 19 interviews with pharmacists, nurses, general practitioners and carers were undertaken across metropolitan and regional settings in Western Australia, New South Wales, Queensland and Victoria. Data were analysed thematically using a framework that allowed similarities and differences across stakeholder groups and locations to be examined and compared.

Results

Three main themes emerged: Effective communication; Challenges to effective communication; and: Towards best practice, which comprised two themes: Community pharmacists' skills and Community pharmacists' needs.

Discussion

A key component of the provision of palliative care was having effective communication skills. Although community pharmacists saw an opportunity to provide interpersonal support, they suggested that they would need to develop better communication skills to fulfil this role.

Conclusion

There is clear need for continuing professional development in this area – particularly in communicating effectively and managing strong emotions.

Practice implications

Community pharmacists are willing to support palliative care patients and carers but need education, support and resources.

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1. Background and objectives

Since the World Health Organisation[1]proposed that primary health should be at the forefront of health systems, patient care has increasingly been moved from hospital to the home.[2] This changing pattern of health care provision has led to an emphasis on providing care in the community to people at the end of life,[3] acknowledging that people prefer to die with the support of family and friends.[4] Achieving a death at home for a palliative care patient is dependent on a range of factors including the availability of skilled support from community based health professionals. [5-7]

The provision of this skilled support from health care professionals for community based palliative care, however, is complicated by unmet demand for General Practitioner (GP) services and an increasing number of patients with chronic diseases and complex care needs.[8] Additionally an ageing population[9] will result in an increased number of people with chronic and/or life-threatening diseases and, consequently, the numbers of patients requiring palliative care. The involvement of community pharmacists in the provision of community based palliative care would seem an appropriate way of alleviating these challenges and supporting end-of-life care in the home.

Although not forming the basis of their substantive work, community pharmacists are well-suited to respond to the palliative care needs of clients, especially as they often have a primary relationship with families. The community pharmacist is one of the most accessible primary care professionals[10] and visiting a pharmacist is convenient for most people, even those who have limited access to private or public transport.[11] They are also easier to access than other primary care providers, especially when GPs' surgeries are closed.[12] With extra

training community pharmacists could, potentially, take on services similar to those provided by clinical pharmacists in hospice and palliative care units in hospitals. In these settings the pharmacist is part of the interdisciplinary team and works closely with other healthcare professionals to undertake patient assessments; systematic medication reviews; patient counselling at discharge and follow-up; and home visits.[13-15]

Two studies demonstrate that community pharmacists can be active and successful members of the community palliative care interdisciplinary team and respond to the palliative care needs of patients with whom they often have a primary and ongoing relationship. In a study conducted in the United Kingdom (UK)[12] an expert panel found that the pharmaceutical care plans devised by community pharmacists for palliative care patients using local pharmacies were likely to be beneficial. A second study involved pharmacists based in a Californian outpatient setting.[16] These community pharmacists initiated or modified treatment regimens for palliative care clinic patients under a collaborative practice protocol and arranged follow-up appointments with the palliative care service. Physicians reported that the service was useful for managing symptoms.

In order to develop the pharmacist's role in the community based interdisciplinary palliative care team continuing professional development (CPD) is needed. Although many community pharmacists will see palliative care patients and carers in the course of their work, the majority will do so only infrequently. Most community pharmacists have little or no training or CPD in palliative care and report a lack of confidence in this area.[17] A recent survey conducted in Japan found that a key CPD need for community pharmacists to facilitate their participation in palliative care was to learn skills to communicate effectively with patients and carers.[18] This is interesting given that a 2010 review of pharmacy interventions[19] with

patients with diabetes concluded that there is a lack of consideration in the literature on the influence of communication skills on health related outcomes for patients, despite findings that pharmacists' communication skills are a key determinant of satisfaction, perceptions of overall service quality and trust in the pharmacist.[20] There is a clear emphasis in palliative care on effective communication and patients are more likely to feel anxious and experience dissatisfaction when effective communication is lacking.[21] Therefore the issue of communication warrants further attention.

The aims of this research, therefore, were to: 1. ascertain community pharmacists' understanding of effective communication for palliative care patients and carers and 2. explore what community pharmacists need to facilitate effective communication for palliative care patients and carers.

2. Methods

2.1 Research design

A multiple qualitative case study design[22-24] was used for the study. We examined the interaction of complex factors associated with effective communication for palliative care patients and their carers while retaining the holistic and meaningful characteristics of such communication and interaction.[24] Our design permitted the articulation and elaboration of the individual perspectives of the respective stakeholder groups in the localized context of palliative care provision in Australian metropolitan and regional areas.

2.2 Data collection

Ethical approval for the study was granted by Curtin University and all relevant site Human Research Ethics committees.

Focus groups and individual face-to-face or telephone interviews were undertaken with pharmacists, nurses, general practitioners and carers. A total of 16 focus groups and 19 interviews were undertaken across metropolitan and regional settings (see table 1).

2.3 Participants

Our purposive maximum variation sampling strategy utilising contacts, snowballing, advertising in professional newsletters, cold calling using contact lists, and flyers resulted in a total of 122 participants who were reflective of a different range of qualifications experiences, knowledge and demographics. Our sample comprised 54 pharmacists including community pharmacists; accredited pharmacists (pharmacists accredited to provide home medication management reviews for patients at home or in aged care facilities); hospital pharmacists; and pharmacists interested in, or specialising in, palliative care. We purposively selected pharmacists from a range of backgrounds, with varied experiences of palliative care in order to gain insights from participants who had extensive experience in palliative care, as well as from participants with little or no experience of palliative care, on their understanding of the key communication issues when supporting palliative care patients and carers and what community pharmacists need to facilitate effective communication with palliative care patients and carers.

A key tenet of palliative care philosophy and practice is the interdisciplinary team approach (including patients and carers). As such, we wanted to explore the views of other members of the community based palliative care team who would be working with the community pharmacist on the key communication issues when supporting palliative care patients and carers and what community pharmacists need to facilitate effective communication with palliative care patients and carers. As such, we recruited 44 palliative care nurses working in

community based palliative care, residential aged care adopting a palliative approach or working in a dedicated hospice or palliative care unit in a hospital; 10 practising GPs, a minority of who were working in a palliative care service, and 14 carers of palliative care patients.

The participants were drawn from both metropolitan and regional areas across Australia thus providing a cross section of views that may be reflective of particular practices of palliative care in various parts of the country. Demographic characteristics of the participants are described in Table 2.

We reached saturation (where no new information is forthcoming) before completing all the focus groups. However, we continued after reaching saturation as we arranged the focus groups in advance.

2.4 Materials and process

Focus groups were used as the main source of data as they enable a group of participants to share their views, thoughts and experiences[25]. Individual face-to-face interviews were conducted with participants when they could not attend a focus group due to time constraints (most GPs were interviewed face-to-face), lack of access to transport, or illness. A small number of telephone interviews were conducted with participants in a rural setting in Queensland due to the problems with distance, and with carers due to time constraints. A semi-structured interview schedule was developed by MOC, CF and GH using an iterative process. Feedback on the schedule, and its key questions, was then sought from the wider project team and, based on this feedback, questions were revised and updated. The final interview protocol provided a schedule of the key issues to be addressed in each focus group

or interview but was flexible enough to accommodate the natural flow of conversation and the inevitable pre-empting of questions by participants. Issues addressed included: the potential role of the community pharmacist in the community based palliative care team; any barriers to being involved in the palliative care team; what would facilitate the involvement of the community pharmacist in the palliative care team; community pharmacists' communication with patients and health care professionals – both the current situation and the ideal scenario; and what CPD would be needed or community pharmacists. We asked community pharmacists about their experiences and understanding of palliative care and experiences communicating with palliative care patients and carers. We asked other role groups about their experiences communicating with community pharmacists. The development team and 2 research officers (JL and MF), all experienced interviewers, conducted the interviews and focus group sessions. They kept the discussion relevant and probed for clarification and examples.

At the beginning of each session there was a general introduction to the project where information sheets were handed out, ethical aspects outlined and consents obtained for participation and digital recording. A demographic sheet was also completed at this time.

2.5 Data analysis

The focus groups and interviews were recorded and transcribed verbatim. Data were analysed thematically by the first four named authors as a team, using an inductive method[26]. An analysis framework that allowed similarities and differences across stakeholder groups and locations to be examined and compared[27] was developed. This provided flexibility to accommodate additional and emerging themes but centred on the key research questions. Transcripts were initially read line by line and units of meaning identified and coded. As the

analysis continued, the units of meaning were clustered into major categories of meaning and further into themes. Any initial disagreement as to the appropriate coding of excerpts of text was discussed in team meetings until consensus was achieved. The computer based qualitative data analysis program NVivo8 ® facilitated analysis. Rigour was ensured using the criteria recommended by Sandelowski.[28]

3. Results, discussion, conclusion and practice implications

3.1 Results

Three main themes emerged in this study: Effective communication; Challenges to effective communication; and Towards best practice, which comprised two themes: Community pharmacists' skills and Community pharmacists' needs. These themes were overlapping at times but are presented separately for the sake of clarity. Under each theme, findings from pharmacists are presented first and these findings are supplemented by data from cares, nurses and GPs.

3.1.1 Effective communication

Community pharmacists in this study articulated a clear, multifaceted role for community pharmacists in palliative care, which extended beyond the dispensing of prescription medication to providing psychosocial support to the patient and his or her carer and family. A key component of the provision of this support was seen as having well developed and effective communication skills. Communication; however, was not perceived as a straight forward concept, rather it was understood by community pharmacists as being multidimensional and layered.

Effective communication was seen to involve information giving – what pharmacists call counselling:

….we sort of help them to guide and like what is the best thing, maybe what they can try, what, what's the thing they can do to solve their problems. Community pharmacist, NSW, metropolitan.

In addition to counselling, which is intrinsic to community pharmacy practice, participants highlighted the importance of a number of other communication skills. Some pharmacists mentioned listening to patients and carers: *…."just basically listening to them and telling them what the tablets are for."* (Community pharmacist, NSW, regional). Other community pharmacists went further and emphasised reflective listening and the validation of people's decisions:

They say, "What do you think?"….a lot of times people use you as a sounding board… you do nothing more than listen and listen to their decision and, and where, where it's warranted….you just, you give them that level of confidence that they're making the right decision. Community pharmacist, NSW regional.

Other pharmacists perceived the community pharmacy as a safe place to talk and vent, and saw the community pharmacist as the recipient of these outpourings:

The people, they, they're coming in for their medication for their partner or their parent or whoever, but it's quite often a chance for them to talk about what's going through their lives in trying to, to deal with, you know, a close, someone close to them dying and also all of the complications. Pharmacist, Victoria metropolitan.

This was particularly the case after bereavement:

And then you also get the same thing when they bring back all the medications after the person's died as well….Yes, they like to unload ….if they can. Community pharmacist, Perth, regional.

Some pharmacists emphasised more psychological aspects of communication, such as compassion *"….because you do have to be compassionate"* (Pharmacist, Victoria, metropolitan) and skills for providing emotional support:

I strongly feel pharmacists must develop….skills in supporting and advising dying patients and their families. If pharmacists are confident in approaching these situations they are more likely to interact and therefore contribute to the palliative care process. Community pharmacist, NSW regional.

Others expressed the need for sensitivity, starting from where the patient/carer is and asking questions before giving advice:

….and needs to sort of kind of assess where that patient's at psychologically….So that pharmacist needs to be very sensitive and aware ….Ask them questions to begin with to assess where the patient's at before launching in to make their suggestions. Pharmacist, WA regional.

Carers mentioned that information giving and explaining what medications are for was a major role for community pharmacists:

Yes…, they [community pharmacists] do everything to help and explain to you. You go to the pharmacy and you ask for any help they tell you, they explain to you as well. No problem. Carer, WA, metropolitan.

Carers also wanted their community pharmacist to listen, have empathy and communicate well:

I think all they need really is to be a good listener….Be a good listener and to have social skills…. to treat you nicely, to treat you well, to be understanding, to be able to talk to you, to sympathise, to empathise. Carer, WA, metropolitan

3.1.2 **Challenges in communicating effectively**

Communicating effectively with patients, carers and their families was at times problematic for community pharmacists. The difficulty of juggling and finding a balance between

responding to emotional needs, and the necessity to focus on the medications side of the pharmacy was a consistent and strongly articulated theme:

You actually do have to …make time to, to see these people and I think that's one of the, the hardest things is to find that, that balance because you know you've got a million other things to do yet you have to be compassionate as well and you know, everything else tends to, you know, your, I suppose your manual work that… you should be doing, tends to be put aside and you can sometimes make errors in that sense because you leave that aside while you're talking to this person…. Community pharmacist, WA metropolitan.

These challenges were exacerbated after bereavement. People's grief was seen as extremely difficult to deal with, especially when the person was not known to the community pharmacist:

.....you know, a bagful of medication that they desperately want out of the house or they don't want to give away, you know, and all of the, the support that goes along with that….and that has quite an impact on you….you're trying to be compassionate and take time……. Com Pharmacist, WA metropolitan

A related issue is around switching from one mode of communication to another: *Yes and, and trying to, you know, getting serious and compassionate and hold their hand and look into their eyes and all that, you just got to switch.* Com pharmacist, WA metropolitan.

The nurses also highlighted that communication with people soon after the death of a family member can be very difficult and emotionally draining:

We do a lot of debriefing in the pharmacies….they know people over the years and they keep coming in and all of sudden when you take the drugs back they all, some of them are visibly upset…. And the pharmacist looked as if I'd punched her when we [told her]….she physically reeled. Nurse, WA metropolitan.

Further, many nurses and GPs mentioned the difficulties created when community pharmacists do not communicate effectively, most notably around medications used in palliative care:

Yes and I, and, and the other issue I've had is sometimes them saying to a patient, "Oh you mustn't use that too often or…"Querying the dose to a patient. They've just come back to get a new prescription and they've used the bottle of Ordine® quickly….it can be a bit off-putting sometimes when the patient relates back to you that the pharmacist has told them that they're using too much. GP, WA metropolitan.

Haloperidol gets prescribed. One of my clients rang up in an absolute rage because the pharmacist has said, "There's nothing wrong with your brain, what have they put you on that for?" And we've given it for, you know, as an anti-nausea agent…. [patients] are often quite stumped when their pharmacist says, if they're having one of the anti-epileptic drugs, "Gee I didn't know you were an epileptic." And you know, they're not, and they actually don't really want the pharmacist to say that. I find pharmacists say things out loud, you know, at the counter. They want you to have a consultation and then they ask you questions in front of people. Nurse, WA metropolitan.

3.1.3 Towards best practice

3.1.3.1 Community pharmacists' communication skills

There was some disagreement among stakeholder groups concerning the level of skill community pharmacists have with regard to effective communication. Some community pharmacists considered their skills to be well developed and effective saying: *"I think pharmacists already do that [the psychosocial aspects of care]"* (community oharmacist, NSW metropolitan) and

I'm a good, I'm not a bad communicator so I'm lucky, I can get into people a little bit….and I'll say, "You know, you're really allowed to be angry now." And they almost break down. "You, to me you, you've got every right to be sort of really bad and friggin' hate the world, you know….but that's normal," and they walk out thinking, "Thank Christ for that." Community pharmacist, WA regional.

Many community pharmacists; however, expressed doubts about the skill levels of community pharmacists in communicating effectively with palliative care patients and their carers – some were unsure of their own skills and some unsure of other community pharmacists' skills: *"Because for myself, I have no idea what to say to the family"*

(Community pharmacist, WA metropolitan) and "*people don't know what to say, so they say nothing"*. (Pharmacist, Victoria metropolitan).

The participant below expressed ambiguity about his/her communication skills:

…. for me it's been a matter of, you know, "…. if we can help, if you need something….you know, give us a ring."….or, "Do you want to come back later on today when it's a bit quieter and we can have a talk," Yes [I don't cope] very well - and it's usually sort of a bit of a scramble, it's never cool and collected when it happens. Community Pharmacist, WA, metropolitan.

This was attributed to a variety of reasons including inexperience and lack of maturity and a lack of education:

She more-or-less said, "Oh have a good time," or something and then – "Oh," she goes,"Oops. They're going home to die and I'm telling them to have a good time" or something to that effect, you know….so it's just the immaturity that just came out. Community pharmacist, WA metropolitan.

No, well I'm just saying, when we went [to university] communication skills were not a big part of what we were taught. Community pharmacist, NSW regional.

One carer spoke of a lack of empathy, despite the community pharmacist being friendly. This highlights the difference between good social skills and effective communication, which includes empathy and is more than being friendly and outgoing:

I think it's a very valuable service and most pharmacists are absolutely delightful and lovely and can't help you enough but it's that they don't always know what you're going through. Carer, WA regional.

3.1.3.1 Community pharmacists' needs

Despite some community pharmacists feeling confident about their communication skills, many pharmacists expressed a clear need for CPD in this area. The following participant summed this up clearly by saying:

So I think maybe we need some …skills …at times I have to think while, while that person is talking, I'm thinking of things to say to them which, which will somehow encourage or help them or strengthen them without sounding over patronising and saying, "Oh you know, they'll be okay -." ….you want to give them something constructive. Community pharmacist, WA, metropolitan.

Pharmacists highlighted the need for strategies for ways to communicate and assist people to cope with bad or difficult news:

…. you know, just simple strategies to – Ways to approach to help cope with communicating information that people don't want to hear. And helping them to listen to what you're saying, rather than necessarily you know, not liking it and therefore not listening and getting the wrong message and that sort of stuff and they've, you know, know, that there's a few simple just small tricks and small approaches that you can use as rules of thumb. Community pharmacist, NSW regional.

Bereavement knowledge and ways to support grieving family members also emerged as something that community pharmacists struggle with:

…. and what, what I don't know is….the stages of, you know….bereavement…. if you at least understand the stages that the person's going to go through and the carers are going to go through, it's a, it's a big help to, not necessarily to put words in your mouth but at least fore, forearming you with a bit of knowledge that's going to maybe, you know, maybe allay certain fears, maybe helping you avoid, you know, moments of embarrassment for, for you or for the other, or for the patient or for the carer. Accredited pharmacist, WA metropolitan.

Strategies to support people emotionally came up – including how to deal with very distressed people and people who are depressed:

In some ways a, dealing with it, a psychological, a psychosocial sort of management. You know, how do you deal with, …, I don't know if you ever have someone sort of break down in front of you or anything you know…. And, and it's how you actually respond…..it's not like, oh yes, you've just got a bit of chicken pox or something like that.. Slap this on and you're

going to get better. It's not like, like, you know, oh they'll be alright. Accredited pharmacist, WA regional.

And depression. Be nice to be able to [have] a handful of positive things we could say. Community pharmacist, WA metropolitan.

3.2 Discussion

Pharmacists emphasised the importance of effective communication with palliative care patients and carers and this was consistent across all settings and geographical areas. Communication was articulated as being multifaceted and not just focused on giving advice about medications. There was also an emphasis on active listening, emotional support, empathy and sensitivity to needs. This supports findings that communication falls into five main themes: information exchange; decision making; giving advice; and handling emotions, all of which were mentioned by our participants.[29] The pharmacists highlighted a two way communication process – listening *and* talking/advising, which reflects the literature on nurses' communication skills, which emphasises the giving of information alongside encouraging patients to talk about their emotions.[30] Further, pharmacists mentioned compassion and sensitivity, reflecting findings on the importance of interpersonal skills and kindness and compassion in palliative care.[31]

These aspects of communication reported position the community pharmacist as a key community resource for the provision of psychosocial support for patients and carers, and fits with the palliative care philosophy of holistic care, an interdisciplinary approach and communication with respect.[32] Communicating effectively in palliative care is acknowledged as being difficult for palliative care team members. A 2005 study reported that doctors found communicating with patients to be a difficult aspect of palliative care.[33] Similarly a key

finding from a qualitative study by the first author of this paper was that GPs found dealing with family members of palliative care patients to be extremely stressful.[34]

One difficulty that emerged strongly was the need to 'juggle' the time constraints of running a busy business with the need to be compassionate, and this was particularly challenging after the patient had died and the bereaved family member wanted to talk. This juggling and the need to change focus are certainly not particular to community pharmacists; research with health care professionals, looking at eliciting and responding to emotional cues, highlights strategies for prioritizing and supporting patients and carers in busy health care settings.[35] As such, prioritizing time may be a valuable focus for CPD.

Our study found that there was a clear need for training in communication skills, which is reflective of the literature. For example, a recent survey of Japanese community pharmacists identified the need for training in communication skills.[18] It is clear from our findings that many community pharmacists would benefit from CPD in communicating effectively using a variety of strategies; being sensitive and discreet, responding to emotions and supporting people who are recently bereaved. Research in eliciting and responding to emotional cues includes examples of what to say when people are distressed, how to normalise feelings and strategies for ending a consultation and creating closure.[35] Researchers have also developed CPD, which addresses a range of issues including focussing on the patient and reflective listening.[36]

Many pharmacists mentioned the scenario of when the carer brought medications back to the pharmacy and wanted to talk about the patient. Nurses and GPs also described the difficulties community pharmacists faced at this time. These finding reflect those of O'Connor et al, who

found that GPs who see palliative care patients and carers wanted information and training on bereavement issues and strategies for providing sensitive and appropriate support.

3.3 Conclusion

Effective communication is a priority in palliative care – health professionals need to assess needs with sensitivity and provide support, often in difficult or busy circumstances. Community pharmacists are well aware of the need for effective communication with palliative care patients and carers. They are also acutely conscious of the multivariate nature of communication and that it is not just about advice giving or being friendly. However, there are a range of situations where community pharmacists are unsure about, or lack confidence in, communicating effectively. Other palliative care team members also gave several examples of how communication could be improved. As such, there is clear need for CPD in this area – particularly in communicating effectively with patients and carers and managing strong emotions.

However, we must be mindful that CPD at the individual level must be accompanied by systemic and organisational support from local and national professional organisations and a concerted attempt must be made to integrate the community pharmacist into the interdisciplinary palliative care team. If we see this as just the community pharmacist's individual responsibility improvements will inevitably be piecemeal and slow.

3.4 Practice implications

We recommend a consistent education framework for tertiary education courses as well as CPD aimed at current practitioners. We also recommend systemic support and resources at local and national levels to support a well developed CPD agenda and framework and a

consistent roll out. Finally, we recommend a coherent and robust research agenda looking further at the community pharmacists' role in the palliative care arena, particularly their role in bereavement support.

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I confirm all patient/personal identifiers have been removed or disguised so the patient/person(s) described are not identifiable and cannot be identified through the details of the story.