

Person Centred Information for Discharge Home

Research in Progress

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Abstract

Clear person-centred information relevant to a person's unique situation is an essential component to continued care following a hospital stay. Rising pressure on health services to discharge patients earlier is placing patients at risk as the ability to absorb information in hospital can be significantly impaired. Many patients return home with inadequate information to support recovery. To date the problem of patients returning to hospital following discharge has not been looked at from the perspective of person-centred information provision and the extent to which better quality, timing and delivery of information (what and when provided) could reduce the rate of return. This qualitative exploratory study uses Roy's Adaption Model to examine the question: *What are patients' unique person-centred information needs at three critical time points pre- and post - discharge.* Understanding unique person-centred information needs provides insight for IS content design to facilitate smoother healthcare transitions between hospital and home.

Keywords person-centred, discharge, hospital, home, information.

1 Introduction

Mandy: 'All I have been told [is] that the best thing I can do is not smoke.... but that's just common sense really. I um, I don't know [for sure] what I can and can't do.... am I allowed to drive? I don't know, when is it safe to go back to work? I don't know.....'

This excerpt illustrates a significant problem: patients being discharged from hospital without sufficient information to facilitate recovery at home. Information provision (written/verbal) is designed to assist the recovery process at home, but is often insufficient to meet detailed personal requirements. In addition, reductions in resources, shorter length of stay and increasing pressure for quality care is resulting in a greater reliance on organisational processes to maintain patient access and throughput (AIHW2016). Discharge planning is a clinical process designed to acknowledge personal home- life situations and is aimed at identifying a patient's immediate needs post hospitalisation (Maramba et al. 2004; Parkes and Shepperd 2000). The transition home is a particularly vulnerable time for patients as they adjust to the illness and resettle into demands of life after hospital (Aminda et al. 2005). Often, patients rely on written education from the hospital to help them understand warning signs and symptoms, medication regimes, and recommended healthy behaviours to reduce their risk of subsequent events (Mistiaen et al. 2007; National Heart Foundation of Australia 2017; Parkes and Shepperd 2000). Information interventions are designed to assist patients' transition however few interventions fully appreciate person centred information needs and requirements (Mistiaen et al. 2007). The Australian Commission on Safety and Quality in Healthcare (ACSQHC), recommend information provision should be tailored for individuals and delivered through partnerships between provider and consumer (ACSQHC2010). The exact timing and content to deliver person centred information is not clearly understood. Understanding how information delivery needs change over time provides insight into a tailored approach to individual information delivery and use. This paper is designed to address the research question ***what are patients' unique person-centred information needs at the time points of pre-discharge, 24hrs and seven days post discharge?***

1.1 Background Literature

Person-centred care is a model designed to enhance communication between healthcare professionals and patients' (McCance et al. 2011). The approach has been shown to increase adherence to protocols, reduce morbidity and improve quality of life (Ulin et al. 2016; University of Gothenburg 2016). True person centred care involves a bi-directional approach of sharing information between healthcare practitioner and patient in order to plan, prepare and discuss needs during the course of the hospital stay (ACSQHC2011). Information provided at or near the time of discharge is a recommended safety intervention measure to provide patients with a level of empowerment, visibility and deeper understanding of the effects and significance of their condition (Jack 2009). It also allows a person to become more perceptive to interventions specifically tailored to suit their individual needs and requirements (ACSQHC2010). However, information captured in the medical record illustrates that artefact lacks sufficient detail and context to communicate person-centred requirements (Taylor et al. 2017). Discharge information currently exists as structured general instructions (what to do, what not to do) and is delivered through several mediums including written, verbal, video, text message, mobile phone applications and follow up phone calls. Although recognised as an important component of care, exactly what and when (information/instructions) to include is not clearly understood and open to individual clinician-patient interpretations (Ekman et al. 2011). Further, an inability to digest discharge information provided during hospital admission can result in important content being overlooked (Aminda et al. 2005; Horstman et al. 2017).

Person centeredness is described as '*..... those attributes that represent our humanness and the way in which we construct our life*' (McCance et al. 2011, p. 2). Person centeredness is a widely implemented strategic direction for clinical operations of healthcare organisations and recognised as a way of facilitating healthcare delivery to address individual information needs and care provision (ACSQHC2011; McCance et al. 2011). A person-centred approach is a partnership between healthcare professional and patient to achieve care quality, such that the person's unique requirements are met within a health delivery framework (Broderick and Coffey 2013; McCance et al. 2011; McCormack and McCance 2006; Ulin et al. 2016). The framework is designed to meet patients' information needs and continue education following hospital stay (Knier et al. 2015; McCormack and McCance 2006). However, because this process is not systematised to include unique requirements at discharge, the process, timing and content delivery is consequently subject to limited available time, perceived need

by clinicians and the variance in individual readiness (of patients) to receive and/or process information (Broderick and Coffey 2013; Driscoll 2000; Knier et al. 2015).

Patients presenting with cardiac conditions have to process this serious life-threatening event within the parameters of their daily life demands outside the hospital (Fållun et al. 2016). Often the unexpectedness of the incident calls for a re-focus on personal aspects of their lives including behaviours, diet, activity and lifestyle (NHF 2017). Education interventions help to guide patients towards adopting healthy behaviours and health plans such as smoking cessation, are identified as a secondary prevention measures against cardiovascular conditions (Deloitte Access Economics 2011; Woodruffe et al. 2015).

Embedding personal preferences within electronic health solutions requires addressing the combination of complex human preferences alongside logical structures so that data conveys context and meaning (Masden 2010). Manipulating data in an information system has shown to be beneficial as in Rudland, 2002, where perceived care by patients improved after nursing care priorities were captured and enhanced to meet patients' preferences (Ruland 2002). With reductions in length of stay there is the need to identify a structure to elicit person-centred information to achieve more meaningful information for patients' use at home. Information solutions are designed to handle the complexity of human nuances (external/internal) and manipulate information to support and enable human processes (like discharge planning) using applied logic and timing (Ammenwerth et al. 2006; Avison and Fitzgerald 2003). Knowing what content and timing for information delivery is most useful to individuals, is the focus area of this study. In this way information systems may offer a sentinel extension of human connection (between clinician and-patient) beyond hospital walls.

The period following hospital discharge is known to be a stressful time for patients where a large amount of adaption occurs. For this reason, Roy's Model of Adaption theoretical model provides a suitable lens with which to understand patient's experience of information delivery (Roy 1984).

1.2 Roy's Adaption Model of Care

Roy's Model of Adaption (RAM) focuses on the person as a series of interrelated systems (biological, social and psychological) that are mobile and constantly shift in response to stressors (internal/external) with the intent on achieving balance (Masters 2014; Roy 1984). The model suggests that the way patients respond is dependent upon how they understand daily demands and stresses. A person's unique adaptive modes reside in four categories of *self-concept*, *role function*, *physiological* and *interdependence* (Roy 1984).

To apply this model to information delivery it's important to consider how a person uses information at time points and the relationship the information must facilitate for the transition to home. Looking through each of the four modes as a lens: *Self-concept*, we considered indicators of self-regulation, self-identity and self-control with a focus on patients' ability to understand and process the event; for *Role Function*, we look at how their role for example as a carer or an employee impacted on understanding the discharge to home event. For *Physiological* we considered how issues such as diet or activity effected their adaptation and for *Interdependence* we considered the information provided to enable them to 'get on with life', such as financial concerns – or continuing a shared partnership with healthcare providers. This model is relevant for use in understanding person-centred discharge information as it is based on a holistic view of the person and understanding the complex inter-personal and extra-personal circumstances that constitute complex daily human functioning. A key factor of RAM is that nurses should be able to identify and capture key areas that impact the person's ability to support adaptive behaviours to demands at home. Given existing pressures on nurses, such as time and staff resources, it can be difficult to identify thus a guide on structure to assist in this process is warranted.

RAM has been chosen as a guide as it focuses on 'the person' and includes identification of specific demands and stressors during hospital-to-home transition (Roy 1999). RAM has been selected to provide preliminary insight of a structure on how patients use information at what times and what information helps them to adapt to new disease and life at home. Other studies have reviewed patients' information needs at two weeks (Horstman et al. 2017) or immediately prior to discharge, (Aminda et al. 2005; Fållun et al. 2016), but to the author's knowledge, few have monitored information needs and overtime in reviewing information delivery in the person's adjustment.

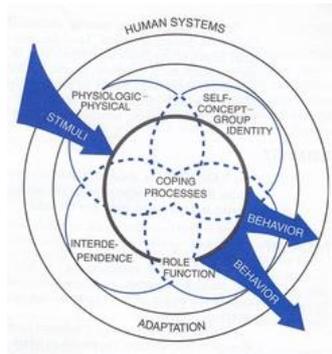


Figure 1 Roy's Graphical Model of Adaption (Roy & Andrews, 1999)

2 Methodology

2.1.1 Research design

We followed a qualitative exploratory research approach (Creswell and Clark 2007; Kaplan and Maxwell 2005; Miles et al. 2013) to investigate the journey of 12 Acute Coronary Syndrome patients who underwent a minor cardiac procedure at a Melbourne public hospital during the period between September 2016 and July 2017. We were interested in understanding how person-centred discharge information impacts on a patient's ability to adapt to their health conditions i) once discharged and ii) continuing with their lives when back at home. For this purpose, the first author, with the support of a cardiac research nurse who works at the hospital, recruited 12 patients (7 females and 5 males) in the 30-59 age group to participate in this study. Our research design focused on person-centred information needs from pre-discharge through till seven days post discharge home.

2.1.2 Data collection

Due to our qualitative interpretive research design, we used interviews as our major data collection instrument. Hence, we first interviewed all participants pre-discharge at the hospital, and conducted two follow-up phone interviews 24 hours post discharge (follow-up interview 1) and again 7 days post discharge (follow-up interview 2). The aim with the follow-up interviews was to identify to what extent discharge information helped participants to readapt at home. Following the interview data collection, we complemented our interview findings with an analysis of each of the participant's medical record admission information and subsequent documented daily progress information. This data collection process was onerous and could only take place 4-5 weeks following the second follow-up interview. Due to our ethical guidelines and strict privacy regulations, participants were given a unique identifier to protect anonymity and confidentiality.

Participants were purposefully selected after reviewing their condition with a cardiac research nurse and the nurse responsible for their care on the ward (Creswell and Clark 2007). The semi-structured interview at each time point had a duration of no longer than 10-minutes and contained 5-10 interview items. All interviews were audio recorded and transcribed verbatim. For each participant, additional data were gathered from their medical record relating to their age, diagnosis, previous history, risk factors, employment status and records of information provided on discharge.

Our interview questions focused on individuals' adaption modes as outlined in RAM: *self-concept* (self-image, esteem, ideal self), *physiological* (diet, activity, unique health), *Role function* (ADL's, work/finance, family); and *Interdependence* (symptom management, preventative self-care, learning styles, needs, goals of care, & support). Using (Corbin and Strauss 2014) funnel design questioning, we asked questions to identify also i) *important information healthcare professionals need to know about each patient* and *what information the hospital has provided giving patients a feeling of support?*" All interviews were audio recorded and transcribed verbatim.

2.1.3 Data analysis

Thematic analysis methodologies were used to code responses into themes that represented RAM modes of adaption: *self-concept*, *role function*, *physiological* and *interdependence*. This was followed by further identification of sub-themes that emerged. Responses were reviewed per/participant to identify changes in data over time, then a constant comparison method to ensure response items were consistently interpreted according to RAM modes for each time point. Findings from the interview

were synthesised into the RAM mode at each time point. The following response provide examples of some of the participants' journeys expressed as common these in the tables that follow.

3 Findings

3.1 Pre-discharge findings

As in the following examples in Table 2 RAM modes of adaption and common themes 24 hrs post discharge

RAM Mode of Adaption	Common Theme	Response
Self-Concept	Feeling of Self	Participant 1: <i>I still don't know what I'm taking and I don't know what I should take afterwards [after discharge]. I have askedbut when am I going to find out all of this?</i>
	Self-Identity	Participant 7: <i>..Um they are still not sure what is wrong with me, um I've got more tests to happen, all they can tell me is that I've had a heart attack....There's no other information filtering through,like this is on your diet and we'd like to you to do A, B, & C. just a bit more detail - detail that's relevant to me.</i>
Interdependence	Partnerships with clinicians	Participant 12: <i>....I suppose in the early stages its just too much to take in. Leave your trust in them and they give you something, well you take it.</i>

Table 1 RAM modes of adaption and common themes at pre-discharge

Medical record findings

Our analysis of this data indicated that the average length of stay in hospital was 3.4 days. One participants had experienced heart attack within the past two years and had already been through the cardiac rehab program. Seven participants were smokers – smoking between 15-30 cigarettes/day, eight number had a diagnosis of STEMI/NSTEMI (other conditions were captured by four number of participants. Four records captured the participants employment status, with three noted as currently unemployed and one on a disability support pension. Little information about their financial role eg: if they were primary breadwinners or primary carers for partners/elderly relatives or young children and the type of work performed – physical work etc, or hours per week.

24 hours post discharge findings

At 24hrs post discharge, participants were adjusting to home outside the hospital, illustrating a focus on self and feeling shocked/overwhelmed. There was a need to normalise the experience (refer Table 2). Participants lacked detailed information about how to enact changes to suit unique situations and stressed a lack of visibility in knowing how and when further intervention would occur.

RAM Mode of Adaption	Common Theme	Response
Self-Concept	Self-identity	Participant 6: <i>...distressed in the moment.... there's still a little bit of nervousness around stuff - feeling like I'm walking on eggshells feeling like I'm uncertain how much I can and should be doing.</i>
	Feelings of self	Participant 1: <i>...that I'm been a little bit depressed. This is all still just a little bit of a shock at the moment... In the hospital I just didn't seem to worry about what life would be like[at home].</i>
Physiological	Mealtime suggestions	Participant 7: <i>...it was very general... like instead of eating chips, eat an apple. Rather than use butter use margarine which is great but 1/2 of it I don't eat any way so it really doesn't apply to me.</i> Participant 10: <i>... I'm looking at the dietary information in that book and instead of having toast and jam for breakfast, I had a couple of vitabrits so already we are changing our dietary intake.</i>
	Activity amount	Participant 10: <i>"...once I have been through the cardiac rehab clinic - and I've got a better idea of what I can do and not do I'll pace myself and increase my aerobic output</i> Participant 6: <i>.... but I don't think they want my heart rate raised too much while it's healing... I guess it's a bit hard to tell someone how far they can walk not knowing how fit they were beforehand.... I don't know.</i>

Role	Finance	Participant 1: <i>Now I've got to spend twice the amount of money, if not more, three times the amount of time preparing and cooking it'.</i>
Function	Domestic Duties	Participant 11: <i>Oh just you feel useless - and you feel like you are not contributing to the household</i>

Table 2 RAM modes of adaption and common themes 24 hrs post discharge

7 days post discharge findings

At this timepoint participants expressed the need to commence 're-living' their lives, (Table 3). They made appointments and started to explore how they interact with the world, eg exercise plans, diet plans etc. Frustration was a common theme where information provided was insufficient to address a rising number of questions on how to self-manage and self-regulate. Participants wanted a deeper level of support with guidance about personal self-care behaviours they might need to make. Participants felt that clinicians no longer 'recognised them' – the reality of 'being able to phone the ward for assistance became less of an option.

RAM Mode of Adaption	Common Theme	Response
Physiological	Mealtime suggestions	Participant 1: ... <i>everything like my complete whole diet, ...like not supposed to have like white bread anymore, I've gotta have multigrain or rye.</i>
Interdependence	Activity amount	Participant 9: ... <i>whether it was my own physical activities which had caused this or whether it was something else".</i>
	Partnership with clinicians	Participant 6 ... <i>but they [hospital staff on the ward] seem to not know me, and seemed to not have much interest in assisting me...[after telling me to contact them for support]</i>
Role Function:	Domestic duties	Participant 7: ... <i>I find is an issue is um because I can't do anything I get boredwhen can I return to work? It doesn't tell you that really in the books anywhere. You know it says you can do light housework, but what do you consider light housework?</i>

Table 3 RAM modes of adaption and common themes at 7 days

4 Discussion

This study aimed to answer the research question: *What are patients' unique person-centred information needs at the time points of pre-discharge, 24hrs and seven days post discharge?* to propose how person-centred discharge information needs can be met for patients with an admission for acute coronary syndrome. It uses RAM as a guide to provide more insights into patient information needs during the transition from hospital to home up to 7 days post discharge. In addition, it highlights the gap in information provision as a result of the failure to capture important person-centred detail and context during the hospital stay.

From this work, there is an identified gap between provision of discharge information and how that information relates to a patients' life outside hospital while recovering at home. This is a consistent finding with other studies in this area (Horstman et al. 2017; Horwitz et al. 2013). Information lacked unique person-centred detail to anticipate unique life demands such as in P1 where she was the primary breadwinner, and carer for a father who was an alcoholic. P1 was recovering and simultaneously concerned about her financial situation, making it very difficult for her to focus on her rehabilitation process, illustrated by *self-concept* responses in Table 1. Through the journey, RAM identifies demands and stresses that emerge for unique person-centred information, such as for P1 at 24hr and 7 days, where *diet* and *financial role* increased in focus (Table 2 & 3). A gradual approach of information delivery can address personal information needs as in the case of Horstman et al 2017 where the instructions became a living document that the patients could refer to a home (Horstman et al. 2017, p. 3). As in our study, focusing on common adaption modes at unique time points, such as *self-concept* and *interdependence* at pre-discharge places an emphasis on unique needs and directs information delivery to meet individual needs, at that time.

At pre-discharge a strong theme was of *Self-concept* and *Interdependence* participants were concerned with processing the event and understanding 'what had they done? And how to fix it, and for this they looked to the skill, knowledge and experience of the healthcare professionals. Analysis of the participants' medical record artefact indicated information lacked context to reflect unique situation and further few details on the intervention or plan of care made between healthcare profession and

patient following discharge. For example, smoking was identified in seven cases (P1, P3, P4, P6, P7, P10, P12) however, the medical record lacked a description of information for a plan at discharge towards helping change this behaviour, or even details as to if this was the patient's intention. Woodruffe et al, 2015 describes plans to help provide behaviour change but 'plans' were seldom referred to in the responses from participants (Woodruffe et al. 2015).

Figure 2 illustrates the different emphases on the RAM adoption modes at the three data points emphasising the most focal elements as the darker contrast in the circles. The emphasis around these elements shifted between the different modes of adaption with the changing timepoints, which coincided with participants re-established and settled themselves at home (see 24 hrs in the figure below). Participants sought information to address their unique needs in being able to assume their role in life again, feed themselves, engage in activity and resume a role at home. The collective sub-themes suggest an emphasis on RAM modes of *self-concept*, *physiological* and *role function* for this time.

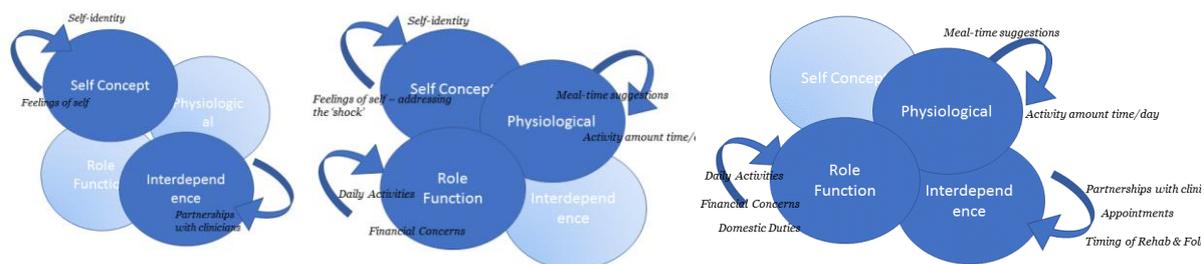


Figure 2 Focal modes of adaption at pre-discharge (left diagram), 24hrs & 7 days (right-hand diagram)

Finally, at 7 days the participants focused on 'getting their lives' back on track - represented by stronger presence of modes of *Physiological*, *Interdependence* and *Role Function* in the adaption to Roy's model. The example responses indicated a focus of attention on diet, exercise and activities to stop them from being bored, where information was missing. There was also a sense of loneliness and separation from hospital staff highlighting that tension of interdependence, where they seemed to not know the participants anymore. These findings are consistent with other work in the area, as in Aminda et al, 2005 where cardiac patients, upon returning home felt loneliness and isolation after the experience.

Understanding changing information needs over time provided insight into the 'person' with a view towards understanding key information interventions designed to assist after hospital (Aminda et al. 2005). Aminda et al, identified that participants expressed different information needs both during and after the hospital stay with some of the concerns at home being feelings of isolation and abandonment and not knowing who to contact when at home. Aminda et al surveyed participants in an older age group than our study, and at 3-5 months post hospitalisation. This study provides further insight into the timing of these information needs identifying that they occur during the immediate post hospitalisation period (7 days) and our younger sample group illustrate the complex situations that patients return home to.

In a recent systematic review into mobile technology assisted smoking cessation interventions, Free et al, (2017) indicated a more than double effect on smoking cessation than medical intervention alone. In the 'txt2stop' project participants personally constructed - meaningful messages which conveyed positive feedback and education about quitting (Free et al. 2013; Guerriero et al. 2013). Patients from our study wanted information delivered in much the same way; providing detail which captured their unique lifestyle and needs a distinct timepoints. A good example here is an instruction to *take it easy* statements for *Activity*. In this example, qualifying exactly what this means for each person requires insight into the context of their activity levels prior to the health event. Knowing these details provides opportunities to engage with patients in hospital on solutions towards mitigating stressors or manage individual behaviour change at home (Rorden and Taft 1990). Information solutions issue notifications to users at pre-determined time points can address persistent needs over time (Avison and Fitzgerald 2003; Free et al. 2013). Using RAM as a guide it's possible to deliver specific content, relative to the individual's needs considering the person's pre-event ability or lifestyle. Placing an emphasis on personal content delivered at pre-determined timepoints emphasises the partnership between healthcare professional and patient and supports previous literature in this area when providing a lean approaches to a healthcare process and partnerships with patients (Simon and

Wickramasinghe 2014). Partnering with patients in this way could help to support information quality and promote patient safety, through personalised plans designed and developed between healthcare professionals and patient. This approach emphasises the partnership within the application of person-centred care models recommended within Australian healthcare systems (ACN2014; ACSQHC2011; Woodruffe et al. 2015). In this way, the adapted RAM models focus content to help convey the *humanness* of caring, by focusing information at person-centred times.

Roy's adaption model provides an approach to understanding person-centred information delivery needs for discharge and how these can be adapted/changed over time. Just as recommendations suggest with applications of person centred models, using RAM requires a change in thinking to promote partnerships with patients in identifying stressors present for the individual, but also to anticipate these in the return home(ACSQHC2011; Woodruffe et al. 2015). RAM draws attention to areas where technology could assist by focusing on person-centred information delivery within the discharge process. This guide provides a first step in understanding timely and tailored content delivery for use at home.

5 Conclusion

This research provides insight into patient's information needs for discharge home. Unique person-centred information needs vary per individual, timepoint and circumstance and the challenge is to find lean approaches to tailored information delivery for individuals that remain relevant or persistent over time. Using RAM as a guide and emphasising common modes of adaption provides insight for IS design by improving quality, timing and delivery. This approach focuses person-centred content on timepoints for patients when they are more receptive to receive it. Thus this work holds important implications for hospital discharge solution design.

6 Further Research

This research continues to examine person-centred information needs up to a time point of 28 days, the National performance indicator measure for readmission to hospital(AIHW2016). It's anticipated greater insight will be visible around the persistent health information needs over time.

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