

Unmet information and communication needs in the intermediate recovery from coronary artery bypass surgery

Randi Martinsen, Cand.san, RN – Anne Moen, Dr. polit, RN

ABSTRACT

Aim: This paper draws attention to information and communication needs reported by convalescents in the intermediate recovery period following coronary artery bypass graft (CABG).

Background: CABG is a common surgical procedure to treat coronary heart disease (CHD). For successful recovery convalescents are encouraged to engage in a set of activities to regain health and a 'sense of coherence'.

Methods: In this descriptive-exploratory study, ten informants (6 women and 4 men) were interviewed three months post-CABG. Data were analysed by content analysis techniques, and synthesised as core themes.

Findings: Undergoing CABG is indeed a challenging experience that influences the 'sense of coherence' in the everyday living and recovery process. The analysis revealed three core themes: 'The drama', 'Unexpected challenges' and 'Information experiences' and point to existential issues in addition to just physical healing. The information provided by health care providers largely focus on physical healing, also in the immediate recovery period. Based on our findings, we suggest that information and teaching resources should cover a more extensive recovery period, and recognize each phase's special challenges for daily living and 'sense of coherence' as the recovery progresses.

KEY WORDS: sense of coherence, coronary artery bypass graft (CABG), communication needs, information, recovery experiences, descriptive-explorative approach

Introduction

Coronary artery bypass graft (CABG) is a common surgical procedure for CHD (1). Compared to less invasive treatments, such as lifestyle modifications, or percutaneous transluminal coronary angioplasty (PTCA), undergoing CABG is a more challenging experience (2) that influences well-being before and after surgery (3).

CABG convalescents are expected to incorporate sophisticated regiments into their daily lives as they manage their own recovery. During preparation for surgery and the few days of hospitalization after surgery, the convalescent receives large quantities of information: verbal and written. This includes information about the procedure, the wounds on the sternum and legs, the sternum incision, and specifically, temporary activity restrictions during the immediate recovery period. During the immediate recovery, the convalescent's capacity to comprehend, process, and incorporate new information is most likely constrained, and their attention is not paid towards learning and information processing (4). The amount and timing of given information are significant, and capacity to comprehend can influence the 'sense of coherence' (5).

Much of the pre- and post-surgery information explains the procedure, specifically self-monitoring in the immediate recovery and recommended lifestyle changes, such as smoking cessation, 'healthy eating' and 'regular exercise' (6). Lifestyle changes are usually required to fully benefit from CABG and to reduce symptoms that may require additional treatment. Convalescents may experience anxiety and symptoms of depression in this early recovery period (1,7).

In addition, 'the heart' carries a significant, existentially oriented meaning to many of us. The capacity to comprehend; process the relevance of or evaluate the usefulness of provided information can be inhibited (1,4,7). Hence, convalescents can report information dearth and a lack of information following CABG (8).

During the recovery from CABG, convalescents monitor their own healing and are encouraged to adopt sophisticated regiments for secondary prevention as part of their daily routines. Recovery experiences alter during recovery (3,9). Women report setbacks from unexpected muscular pain in the chest and problems with maintaining recommended activity levels after surgery (10,11,12). Men can experience the recovery process more smoothly than women, and they attri-

bute this to family support, especially from a wife, partner or significant other (10).

According to Antonovsky's salutogenic model (5,13), the individual's experience of comprehensibility, manageability and meaningfulness is a core premise to handling every day situations. A convalescent's 'sense of coherence' is likely to influence his ability to engage in recovery management on a daily basis, as he incorporates recommendations for secondary prevention of CHD. Acknowledging that CABG recovery may be challenging, this study was theoretically inspired by attention, patient education (4) and 'sense of coherence' (5). We have only identified previous studies setting out to measure SOC as an aspect of assessment of quality of life studies following heart surgery. To the best of our knowledge, there are no previous studies applying this construct to elaborate challenges the convalescents are facing in the intermediate recovery period. To better understand recovery challenges and information needs during CABG recovery, we need to elicit the CABG convalescents' information and communication needs in the intermediate recovery period.

The aim

The aim of this paper is to draw attention to information and communication needs reported three months post-surgery following coronary artery bypass graft, elaborated by the following research question: how do CABG convalescents experience their needs for information and communication to meet day-to-day challenges three months post-surgery?

This study is a part of a larger study with the overall objective to better understand convalescents' and family members' evolving information and communication needs when recovering from CABG, and to explore opportunities for customizing web-based patient learning resources for CABG recovery that better match challenges of daily living (14).

Materials and methods

This study has a qualitative, descriptive-exploratory design (15). We used semi-structured interviews to collect data about recovery challenges and information and communication needs three months after

CABG. The findings presented here are from ten informants (6 women and 4 men), aged 45 to 64 years, and we interviewed them three months after CABG surgery.

The semi-structured interview guide included questions to elicit experiences about

- CABG recovery, healing and strategies to manage encountered experiences
- recommendations for secondary prevention
- preparation for recovery, information and teaching approaches (seen in hindsight)
- peer-to-peer contact, participation in recovery programs, etc.

The interviews took place from November, 2003 to February, 2004. All informants were interviewed in their homes and each interview lasted for about one hour.

Ethical consideration

Following approval by the Regional Ethics Committee for Medicine (REK II) in Norway, the staff at the heart clinic recruited convalescents who had undergone CABG just once and lived in the counties closest to the clinic in order to participate in the study. Those willing to participate were then contacted to schedule the interview. All participants signed a consent form before the interview.

Data analysis

All interviews, except one, were tape-recorded and transcribed verbatim. In one interview, the informant had reservations about tape recording, so the researcher only made notes during this interview. For the analysis, each transcript was read for general impression, and then the meaning units as manifest and latent content were identified, condensed and coded. The codes were then systematized and abstracted into core themes (16). An example of the process is provided in Figure 1.

Each researcher read all the interviews for general impression, condensed and coded the transcribed text to identify core themes. To strengthen the rigor during the analysis process both researchers discussed the coding and agreed that the identified themes reflected the informants' experiences.

Findings

In this group, the female informants were 45–64 years old, with a mean age of 58 (n=6). The male informants were 52–53 years, with a mean age of 52,6 (n=4). When interviewed, all informants were still on sick leave. Except for two females, they all expected to resume their work shortly after the procedure.

From analysis of the collected data, three core themes emerged, and we labelled them 'the drama', 'unexpected challenges' and 'information experiences'.

The drama

The drama included contemplations about existential questions of life in general, life expectancy and survival. Five of the female informants talked explicitly about the CABG surgery as a *dramatic* experience. Recovery experiences like unexpected return of chest pain, although different than experienced pain before the CABG surgery, triggered reflections. For example, they compared their present life to the past, reflected about the future, and what life could have been if surgery were not available. Talking about such experiences was quite specific, as one of the informants shared:

".. I do not think I have fully understood [...] until the last two weeks what I have gone through [...] All of the sudden, I kind of realize that they [literally] held my heart in their hands" (#9).

Experiencing existential challenges like this example came as a 'surprise' to most informants in the intermediate recovery period.

When grappling with such questions related to present life and future prospects, informants expressed uncertainties of how to resume professional work as well as their familial responsibilities. Except for the youngest informant, the women found it difficult to talk with family members or their spouse about their feelings or how to approach possible, upcoming difficulties. Resuming their role as housewife and mother added to their felt challenges. They explained how difficult, painful or cumbersome daily chores like cooking, cleaning or vacuuming had become, and at the same time they refrained from asking their spouse or other family members to participate in or perform certain household work. Being unable to provide support to their teenage children was a specific difficult source experienced by the younger informants.

At the time of the interviews, the informants had not resumed work outside the home. The female informants wanted more time to fulfil dreams or spend time with friends and family. The experiences shared by the male informants about coming to terms with their conditions related more to their inability to attend to their daily responsibilities because of struggles to come to terms with their condition and cope in everyday situations. One male informant pointed out that

"...stressful work [...] should introduce a substitute when I tried to return to work after sick leave ... difficult since I know the work, and the substitute needs help with everything" (#1).

The male informants talked also about less capacity to keep up with previous responsibilities and found this stressful, especially if the spouse took on 'their' previous responsibilities. Therefore, their experiences of the *drama* aspects of the recovery took a slightly different path. For example, one said "...all information will serve to comfort my wife!" (#2), and another mentioned that "...my 17-year-old son is monitoring me, making sure everything is normal" (#4). In addition, they felt guilt for the situation, and the extra burdens on their families added to their efforts to come to terms with the dramatic experiences.

Unexpected challenges

The theme *unexpected challenges* relate to the informants experiences to engage in recommended secondary prevention activities. The informants raised issues such as unease, uncertainties or worries about the future that led to emotional disturbance. One of the informants said this:

"About my mood, everything is looking dark. I've heard it will last for ten years. I'm wondering how it really is [...] some days everything is looking dark, though my condition is better" (#7).

To handle such unease and anxiety, they chose to stay alone, or limit social interaction to immediate family member post-surgery. Male informants explained that the fatigue they experienced was probably due to spending too much energy consciously and unconsciously ensuring that they and their family members were 'OK'. Energy was also spent thinking about how the body and heart would react to diffe-

Figure1: example of the process from text data to theme

Text (meaning unit)	Condensed	Code	Core Theme
"About my mood, everything is looking dark. I've heard it can last for ten years. I'm wondering how it really is [...]"	feeling depressed uncertainty	existential	drama
"I hate exercising! I've never enjoyed it. I think it's a waste of time [...]"	difficult to exercise	secondary prevention – activity	unexpected challenges
"I remember very little of what they said [...] Can't remember anything because my mood was up and down"	poor memory	hospital's information	information experiences

rent situations, how their future work life might be influenced, and how to move on because they were still tired.

Several informants found it difficult to follow recommendations for regular exercise, dietary changes, and smoking cessation. None of the female informants had exercised regularly before surgery, but four mentioned increased activity post-surgery. One of them did not exercise at all, and explained this as a lack of interest. Two of the female informants talked about organized activity, but did not join in because of lack of transportation, preference for spending time with their spouse, or felt intimidation when exercising with more physically fit persons. Several of the informants found it meaningful to be part of an organized, gender-mixed exercise group. However, their physician's questioning of participation in organized exercise groups and the age disparity came as an unexpected challenge, like they said:

"I've got a letter... about the exercise group... [but] the doctor told me that it was just for social company" (#9). "It was just ... for the older men" (#6).

The male informants explained that their activity level and exercise patterns had changed post-surgery. All of them exercised regularly. Some were uncertain as to how much they could or ought to exercise, and feared that being too eager or exercise too much would start a negative cycle of declined function. Regaining previous activities took time and they related this to experienced excessive needs for sleep and rest.

The female informants acknowledged the importance of dietary changes to fully benefit from their surgery. However, they found it challenging to actually implement dietary changes, and ascribed this to experienced hesitation from their spouse. The male informants generally thought they had a lean diet, and were therefore unsure what a healthier diet would imply for them. They also explained that their spouse did most of the shopping and were responsible for the family diet.

Three of the females quit smoking pre-surgery, but expressed that it is challenging to engage in smoking cessation. One was still smoking, although the number of cigarettes was reduced. One of the males had also only reduced smoking significantly, and his continued habit of smoking was of great concern to family members also causing him some stress.

Information experiences

Information experiences include the informants' experiences of the information they had received to prepare for the recovery, as seen in hindsight. In lieu of their experiences, the informants shared problems to remember and comprehend information provided to them during hospitalization. The written information was helpful as reference later in their recovery, but despite this, the informants stated that they felt ill-prepared for challenges they experienced beyond the immediate recovery period. For example, one said,

"...information was generally good, maybe a little too optimistic. But there was a lot of information given orally... when I compare what I remember and my wife's additional notes, there are quite a few things I do not recall or paid attention to" (#3).

Most of the informants explained that the provided information focused on the CABG procedure and recommendations for secondary prevention. The informants expressed that the information during hospitalization was not so useful three months post-surgery, since they progressed in their recovery, their questions and concerns also changed:

"...about my chest pain – it is very difficult to differentiate types of chest pain: there is muscular pain, sternum pain, and pain from the heart. I am wondering ... if I can exercise, yeah, I am unsure of criteria, symptoms, pain, etc., I lack information..." (#2).

Questions related specifically to their personal situation or actually knowing what to ask about was difficult in their encounters with health providers. In hindsight, they would have liked to know more about where to seek information and what constitute 'common experiences' during CABG recovery.

Some of the informants had considered calling the hospital, their general practitioner (GP), a cardiologist or other health providers to acquire specific information. Some of them had met health providers that were not as experienced as expected, or unable to attend to their concerns. One female informant expressed:

"I'm unsure if the doctor can answer me. She is a GP, ... she is very clever ... or if I should ask a cardiologist. ... what I am wondering about ... I should just call. I would think they [the hospital] would know" (#9).

As a strategy, our informants told that they instead sought supplementary information from family, friends or colleagues. In particular, family members with medical backgrounds or colleagues with CABG surgery experiences were resourceful to them. Some of them stayed in contact with and exchanged experiences with others who underwent CABG, and they experienced comfort from the support given by spouses and family members.

Discussion

The informants in this study reported less endurance in physical activity, symptoms of fatigue and depression and challenges of following secondary prevention recommendations interfered with the day-to-day activities. Our female informants were most explicit on the existential aspects of their recovery, and the male informants seemed to focus more on self-monitoring their recovery. Worries about expected or unexpected symptoms, limitations, delayed recuperation or even 'backlash' of previous experiences like chest pain, was not expected by the informants.

The majority of informants found the information they received very useful for their immediate CABG recovery period. Once their energy and activity levels increased, their information needs focused more on the efforts for secondary prevention and challenges in resuming their previous activities. In hindsight, information specific to later periods of recovery could have helped address questions pointing to what may be coined as 'all I did not know to ask about'. To better comprehend what to ask about, could make the situation more manageable and increase 'sense of coherence' during recovery.

The informants did not know of opportunities or forums where they could talk about or exchange their experiences. Undergoing CABG is a major life event, although health providers may view this as a "normal" and routine procedure. The informants shared how the surgery and recovery influenced their own lives and family members' lives. Especially older female informants' found it difficult to share their thoughts and worries with their spouse or family members. In line with findings reported here, Koivunen and colleagues (10) emphasize recovery experiences as a personal drama with many thoughts about life and future. Our findings also support the call for opportunities to share experiences pertaining to the intermediate period in recovery to meet patients' needs. These needs are challenges that the health care service should acknowledge, and for example include more information about existentially oriented aspects of CABG-recovery in their patient education to increase the convalescents' meaningfulness and 'sense of coherence' (5).

The findings from this study illustrate that informants benefited and were able to apply the information they received in different ways. The capacity to comprehend information at different times of recovery can be influenced by previous knowledge, experiences, age and gender (4,10,17,18). Identified differences might relate to fatigue and less attention during the immediate recovery and it is important to be aware of such challenges during hospitalization. Taking developing physical and mental capacity as a premise as the recovery advances, CABG convalescents should be provided opportunities to share concerns and uncertainties, or to ask questions specific to recovery experiences. Such opportunities could facilitate convalescents' 'sense of coherence' during recovery (5).

The present analysis indicates that CABG surgery creates uncertainty for both female and male convalescents. However, the uncertainty takes different expressions, ranging from grappling with exis-

tential issues, thoughts about life, to what constitutes “common” experiences and how to interpret recovery symptoms. Attending to gendered concerns is important across the entire recovery and needs further study.

The female informants suggested that closer supervision and follow-up during an extended recovery period would be helpful. They articulated and appreciated opportunities to communicate thoughts and questions, e.g., symptoms, uncertainty or fear for own life and their family. The male informants pointed out uncertainty about doing “the right things right” in terms of self-monitoring and incorporation of secondary prevention, such as exercise during the recovery. All of the informants continued to contemplate about their present life experiences, and several of them shared unexpected emotional reactions. Their experiences in specific situations influenced their ability to focus their attention. Our findings resonate with other studies that also report that experienced and desired support differs among male and females undergoing CABG (10,12,19), and that post-surgery distress can include anxiety, tiredness, depression and irritation (10,12,20,21). Lack of opportunities to ask questions or interact with health care providers after discharge can reinforce uncertainties and decrease ‘sense of coherence’ during recovery. For most patients, the lack of opportunities to seek additional information can be distressing, leading to question the meaning of life in ways that challenge the persons’ experienced coherence (5).

In our study, the special concerns of parents of teenagers add new dimensions to role responsibilities in the recovery period, and there is a need to explore communication and information support specific to this group since the demographics of CABG convalescents changes. Other aspects of role responsibilities may also need more attention. Our male informants shared that they felt guilt towards their spouse and family, and older women found it difficult to ask for practical help as well as share felt uncertainties. This can indicate that informational material should go beyond just acknowledging the importance of spousal support during recovery (10). Opportunities to raise existential questions would contribute to re-establishing a ‘sense of coherence’. This implies that concerns related to age, role and gender need further attention to meet a broader range of CABG convalescents’ information and communication needs.

Our informants expressed difficulties in incorporating lifestyle changes or secondary prevention recommendations into their day-to-day living. The male informants had few concerns about their diet, while the women had difficulties to change activity and exercise patterns. Unease with participating in exercise groups with people in better physical condition, lack of exercise among women, women’s difficulties in fulfilling their roles, and being a convalescent are reported (10,11,21,22). Managing physical symptoms and monitoring recovery in the early recovery period seemed well attended to (19). It is of great value to be aware that successful recovery and regaining sense of coherence involves more than physical function and clinical measures of performance (23). This study adds findings that point to the importance of resources to support convalescents over a longer period. Sharing “common” experiences can ease efforts to cope with the experienced drama, and initiate as well as keep up day-to-day activities involving lifestyle changes and secondary prevention recommendations. Although previous studies report that measures of ‘sense of coherence’ as stable post CABG (24), findings from this study highlight that health providers should be aware of individuals’ needs expressed as challenges to maintain role expectations, and uncertainty or existential questions to support male and female CABG convalescents’ ‘sense of coherence’ (5).

Patient-teaching programs

Our informants expressed satisfaction with the information provided to them during hospitalization. In hindsight, they were also overwhelmed by the amount of information at the time provided. Despite satisfaction with the provided information, our informants reported several unanswered questions that influenced their recovery experiences three months following discharge. Patient-teaching programs have received attention, and their content and organization have been significantly

systematized to ensure the best possible benefit. Still, other studies also report that the provided programs do not sufficiently prepare convalescents for upcoming challenges (19,25). Incomprehensible or incomplete programs do not meet the CABG convalescents’ developing needs, and are likely to inhibit their ‘sense of coherence’ (5).

Health care providers are well familiar with questions and issues in the immediate recovery period, but less attention is given to intermediate or later recovery challenges. Patient-teaching programs often requires the convalescent to make the information relevant to their experiences under less than optimal circumstances (17,18). Given the extent of information related to CABG recovery information overload is likely, and given the convalescent’s ideas related to ‘surgery on the heart’, attention may not be geared towards specific information processing and learning. Therefore, information should be given mindful of the convalescent’s capacity to process information and understand the significance of information. A better understood development of informational needs over the recovery trajectory may lead to patient-teaching initiatives that are more relevant and oriented to individual needs. Such customization will give the teaching content higher relevance (14,26) and make it more helpful to regain health and ‘sense of coherence’ (5).

Rethinking how to provide information and re-designing patient-teaching programs to accommodate when information is most timely and relevant during a recovery may alleviate experienced challenges that our informants share. Customizing information and communication, being mindful of gender, age, interest and information demands, can fill gaps and also avoid information overload. Adding opportunities to communicate experiences, share strategies to manage daily living after surgery and adopt recommended lifestyle changes would make patient-teaching more attentive to individual needs and complement existing approaches to CABG recovery management.

Concluding remarks

More explicit attention to experienced drama of CABG and providing information mindful of changing challenges during a recovery period should be explored as strategies to regain ‘sense of coherence’ (5). The findings reported here point out that the dramatic experience and existential questions post-surgery seem to inhibit the convalescents’ experienced ‘sense of coherence’ during recovery. Hence, we suggest expanding patient-teaching programs to facilitate more timely information, peer support and follow-up systems with health care providers over time. In addition to information about physical healing and recommendations for secondary prevention, our study points out the importance of including existential issues to better understand what constitutes “common” recovery experiences. As such, teaching resources can provide additional perspectives to cope with experienced drama, concerns and worries. Although further studies are warranted, recognizing evolving recovery challenges to daily living and elaborating approaches to offering information customized in timelier manners, over a longer period, may be very instrumental to processes of regaining ‘sense of coherence’ following CABG.

Limitations and implications

We interviewed 25 patients and 18 spouses in the younger cohort undergoing CABG, to investigate convalescents’ and family members’ evolving information and communication needs during recovering and explore opportunities for customized web-based patient learning resources (14). This paper focuses on findings from 10 convalescents (6 women and 4 men) in the intermediate recovery period. In addition, the empirical data was collected some time ago. Although care should be taken when making inferences from this study, many studies report struggles and difficulties following CABG, supporting claims for rethinking patient-teaching approaches. Our study contributes to substantiate challenges in the intermediate recovery. This is an important reason to further develop teaching programs and meet recovery challenges over time, mindful of age, gender and existential questions.

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Contacts

Randi Martinsen, RN, Cand. san, Hedmark University College, Department of Nursing, Faculty of Health and Sports, NO – 2418 Elverum

Anne Moen, RN, Dr. polit, Institute of health and society & Inter-Media, University of Oslo P.O.Box 1153, Blindern, NO – 0318 Oslo
Corresponding author: e-mail: randi.martinsen@hihm.no

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