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# **Cytotoxic chemotherapy for incurable colorectal cancer: living with a PICC-line**

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## **Abstract**

### **Title.**

Cytotoxic chemotherapy for incurable colorectal cancer: living with a PICC-line

### **Objectives.**

1. To determine which aspects of living with a peripherally inserted central catheter (PICC) line cause Modified de Gramont (MdG) patients most difficulty.
2. To explore MdG patients' views of the PICC-line experience.
3. To determine if patients view PICC-lines as a benefit or a burden when receiving ambulatory MdG chemotherapy.

### **Design.**

A two-stage, descriptive study. Phase 1 comprised semi-structured interviews. Phase 2 surveyed the MdG population. Phase 1 interview data informed the Phase 2 questionnaire.

### **Setting.**

West of Scotland Cancer Care Centre.

### **Sample.**

Phase 1, a convenience sample of 10 MdG patients; Phase 2, 62 consecutive patients.

### **Findings and results.**

A response rate of 93.9% for Phase 2. The majority of PICC-line patients held favourable views towards having a PICC- line and adapted well with minimal disruption to daily life. Concerns evident regarding coping at home with a PICC- line, chemotherapy spillage, dealing with complex information and the responsibility of patients/carers regarding PICC-line management. Patients preferred ambulatory chemotherapy to in-patient treatment.

### **Conclusions.**

PICC-lines should be considered for more chemotherapy patients but that service development necessary to ensure individual needs addressed.

### **Relevance to Clinical Practice.**

- Contributes to the PICC-line literature by providing a national patient perspective on a range of daily living activities

- PICC-line patients prefer out-patient ambulatory chemotherapy rather than in-patient treatment
- the longer a patient has a PICC-line, the more able they are to manage activities such as dressing.
- Highlights concerns remain over chemotherapy spillage, partner/carer responsibility for PICC-line maintenance and the proper balance between required information and what the patient wants to know.

**Key words:**

Ambulatory chemotherapy, PICC-line, peripherally inserted central catheter, patient, information, adaptation, coping

## **Introduction**

Restructuring of cancer services in the United Kingdom (UK) has been necessary to cope with the growing demand for chemotherapy (Twelves 2001), with the majority of patients now receiving chemotherapy in the out-patient setting (Young and Kerr 2001). Ambulatory care, that is the delivery of treatment in the patient's home, is the fastest growing health-care service delivery model in industrialised nations (AETMIS 2004).

Insertion of a central venous access device (CVAD) such as a Peripherally Inserted Central Catheter (PICC-line) is necessary before infusional therapy can be given safely in the ambulatory setting (SEHD 2000). PICC-lines are a cost-effective way of safely administering chemotherapy in the ambulatory setting (Galloway 2002) and reduce the need for peripheral venous cannulation (Gabriel 2003, 2000). Although no European data could be found detailing numbers of PICC-lines used, Moureau et al (2002) reported that >50% of American patients undergoing ambulatory therapy had a PICC-line in situ.

Nevertheless ambulatory chemotherapy is laden with challenges (AETMIS 2004) as patients are more likely to experience difficulties or side effects at home without expert help close to hand (marc 2005, McCaughan & Thompson 2000). The insertion and ongoing maintenance of PICC-lines can have a considerable impact on patients' lives, not all of whom can be assumed to have the physical and cognitive ability to cope with these additional demands (AETMIS 2004, Dobson 2001). Difficulties in bathing, sleeping and dressing are reported (Oakley et al 2000) although the impact on daily life is minimal (Gabriel 2003, 2000). However a lack of evidence exists to support many of the assumptions regarding ambulatory chemotherapy, for example that it improves quality of life (Borras et al 2001).

Little has been published regarding how chemotherapy patients cope with their devices and the impact PICC-lines and other CVADs have upon their lives. Most PICC-line literature concentrates on medical-technical or educational aspects (Collins 2004, Philpot and Griffiths 2003, Carlson 1999) with a dearth of UK-based literature on patients' needs whilst undergoing ambulatory chemotherapy with a PICC-line in situ.

Many patients remain dissatisfied with the information given to them concerning their cancer diagnosis and chemotherapy treatment (Skalla et al 2004, Kruijver et al 2000, Jenkins et al 2001, Elf & Wikblad 2001, Sitzia & Wood 1998); and feel unprepared particularly in the face of increasingly complex chemotherapy regimens (McCaughan and Thomson 2000). This study examined the views and experiences of patients receiving one of the most commonly

used PICC-line ambulatory chemotherapy regimens, the Modified de Gramont (MdG) regimen.

### **Infusion Regime in the Study Site**

The MdG regimen is used to treat patients with incurable colorectal cancer and provides dose intensive exposure to 5-FU every two weeks (Leonard et al 2002). The cytotoxic agent 5-Fluorouracil (5-FU) has been the mainstay of chemotherapy for colorectal cancer for more than 20 years (Leonard et al 2002) and both the National Institute for Health and Clinical Excellence (NICE 2005) and the Scottish Intercollegiate Guidelines Network (SIGN 2003) recommend '5-FU containing' regimens as first line treatment in colorectal cancer. Response to 5-FU in advanced colorectal cancer is increased by the concomitant administration of folinic acid (FA) (Leonard et al 2002, de Gramont et al 1998).

In the study site, patients receiving MdG have a PICC-line inserted in the week prior to chemotherapy commencement. Patients attend the unit on Day 1 of the regimen when FA is given as a two-hour infusion followed by a bolus of 5-FU. Patients then go home with a 46-hour, 5-FU infusion pump attached to the PICC-line which is disconnected by the community nurse on completion of the infusion. The sequence is repeated until completion of treatment.

### **Research Objectives**

1. To determine which aspects of living with a PICC-line cause MdG [Modified de Gramont] patients most difficulty.
2. To explore MdG patients' views of the PICC-line experience.
3. To determine if patients view PICC-lines as a benefit or a burden when receiving ambulatory MdG chemotherapy.

### **Methods**

#### **Study design**

This was a two-stage, descriptive study. Phase 1 comprised semi-structured interviews with a convenience sample of MdG patients and Phase 2 was a questionnaire survey of the MdG study site population. Phase 1 interview data informed the Phase 2 questionnaire. Phase 1 patients were excluded from Phase 2. Data were collected 2004-06.

#### **Ethics Approval**

Ethics approval was sought and given on two separate occasions given the phased study design. As study participants were receiving cytotoxic chemotherapy for incurable colon

cancer, they were considered to be a vulnerable population. All information was treated confidentially and in accordance with the Data Protection Act (1998). Having provided informed consent, no patient withdrew from the study.

### **Study setting and population**

The study was conducted at the chemotherapy day unit (CDU) of the West of Scotland Cancer Care Centre where approximately 250 patients with incurable colorectal cancer are treated with ambulatory MdG chemotherapy via a PICC-line annually. It was decided in line with the research questions, that study participants must be at least eight weeks into their chemotherapy regime to allow a reasonable period for patients to have experienced living with a PICC-line. Exclusion criteria were designed to avoid over-burdening sick patients and we employed the usual, standard assessment tools of the CDU assessment unit.

Study inclusion criteria were:

- incurable colorectal cancer,
- a PICC-line in situ for >7 weeks,
- $\geq 18$  years of age,
- attending the chemotherapy day unit at the study site,
- read and write English
- receiving any MdG chemotherapy regimen.

Exclusion criteria were patients with:

- >grade two chemotherapy-associated toxicities using CDU assessment criteria,
- WHO (1979) Performance Status (PS) of >2.

A convenience sample of 10 patients was recruited from the CDU for Phase 1 interviews. In Phase 2, 69 consecutive patients meeting the eligibility criteria were approached for study participation. On statistical advice, by including all eligible patients as potential participants, it was considered that the sample would be representative of the target population providing there were minimal non-responders.

### **Data collection tools**

The Phase 1 semi-structured interview schedule consisted of 9 prompts that asked interviewees about their PICC-line experience. Four themes emerged from the data which used to develop the Phase 2 questionnaire.

There were 5 sections in the questionnaire: demographics [sex, age, distance from the CDU, ease of travelling to the CDU, number of PICC-lines inserted, length of time PICC-line in situ on completion of questionnaire]; impact on daily life; responsibility/coping at home; information giving; and adaptation/acceptance. Likert-type scales were chosen to report patient views (Oppenheim 1992). For 'impact on daily life', possible responses were 'about the same', 'a little more difficult', 'a lot more difficult' and 'can't do because of the PICC-line'. A 'not applicable' response allowed participants to indicate any activities not carried out before PICC-line insertion. For the sections entitled 'responsibility/coping at home', 'information giving' and 'adaptation/acceptance', possible responses were 'agree', 'strongly agree', 'neither agree nor disagree', 'disagree' and 'strongly disagree'. A neutral position was included (Priest et al 1995). A final, free-text section invited participants to add anything relevant not covered elsewhere.

### **Pilot Studies: Phases 1 and 2**

Following ethics approval, both the interview prompt schedule and questionnaire were piloted successfully in the same health board as the main study and participants excluded from the main study. Three pilot interviews using the semi-structured prompt schedule were audiotaped and transcribed and assessed positively for interviewing style, study feasibility and data quality. The Phase 2 questionnaire was reviewed by an expert panel (Chemotherapy Clinical Nurse Specialist, Oncology Research Nurse, Cancer Nurse Consultant, Colorectal Clinical Nurse Specialist, Oncology Practice Development Nurse) who agreed that the questionnaire had face and content validity in that it was representative of the interview themes. On pre-testing several small amendments were suggested to question wording and these were incorporated into the questionnaire design.

### **Main Study**

#### **Phase 1 Interview process and analysis**

Potential participants for Phase 1 were identified from the CDU admissions list and recruited by the researcher. All participants elected to be interviewed during their next scheduled chemotherapy appointment. All interviews took place in a quiet, non-clinical room adjacent to the CDU. Immediately prior to each interview, the researcher assessed each participant's toxicity grading and Performance Status (WHO 1979) to ensure they were sufficiently well to be interviewed. All were satisfactory. However, one interview was abandoned after 10 minutes as the participant became ill and they were then omitted from the study. Interviews varied from eight to 32 minutes, averaging 19 minutes and all were tape-recorded with



permission. Field notes were completed immediately following the interview rather than during the interview (Holloway & Wheeler 2002). Patients appeared to welcome the opportunity to discuss their chemotherapy treatment.

### **Phase 1 data analysis**

Data analysis (Figure 1) occurred after completion of all interviews to minimise influencing ongoing interviews. All were transcribed verbatim and read alongside field notes (Figure 1). Manifest content analysis was employed as common themes were being investigated rather than applying interpretive analysis; in other words ‘what was said’ was under investigation as opposed to ‘why something was said’ (Polit et al 2001). Face and content validity were achieved as the identified themes were in line with previous work (Oakley et al 2000).

### **Phase 2 questionnaire administration**

Recruitment was carried out by the researcher and took place in the CDU using the chemotherapy appointments list to determine when potential participants were attending the unit.

A reply-paid envelope was provided and it was requested that the questionnaire be returned within two weeks. However, the majority of participants (n=54) elected to complete the questionnaire whilst in the CDU, stating that it would help pass the time during chemotherapy administration. Twelve participants completed the questionnaire at home with 8 completed questionnaires returned within two weeks. A reminder letter was posted for the four non-responders but they were not returned. Ordinarily the PICC-line was in situ for 11 weeks (Range: 8-17) at questionnaire completion.

### **Phase 2 data analysis**

Descriptive statistics were used with patient demographics. Inferential statistics determined the views most likely to be held by the study sample and explored the areas where there was less consensus among respondents. Following initial data analysis, the ‘agree and strongly agree’ ratings were aggregated as were ‘disagree and strongly disagree’ for ‘responsibility and coping at home’, ‘information giving’ and ‘adaptation/acceptance’ statements. On statistical advice 95% confidence intervals were used to quantify the magnitude of population proportions and differences in such, for the views of the study sample.

## **Findings: Phase 1**

### **Response rate**

Of the 11 potential participants approached to take part in Phase 1, one declined. Of the 10 who agreed to be interviewed, one was unable to complete the interview giving a 90.0% (n=9) response rate.

### **Demographics**

Participants' ages ranged from 42-76 years of age. Five interviewees were female. The mean length of time participants had a PICC-line in situ was 13 weeks (Range: 9–23). For the majority (n=7), this was their first experience of having a PICC-line and only two participants knew what a PICC-line was prior to requiring one. The mean distance travelled by participants to receive treatment was 19 miles.

### **Themes**

Overall four themes emerged; (i) the impact of the PICC-line on daily life; (ii) responsibility and coping at home; (iii) information giving; and (iv) adaptation/acceptance of the PICC-line. Each theme became the basis for a section of the questionnaire.

Participants held both positive and negative views towards the PICC-line experience. The main advantages reported were not requiring hospital admission, the reduced need for peripheral venous cannulation and the ease of chemotherapy administration. Nonetheless life changed with a PICC-line and daily activities such as washing, dressing, sleeping and engaging in hobbies were affected. As one said *“having a bath, that was the worst bit.....you’ve got to hang your arm over the side and you can’t get a good wash with just one hand”*. P2 Most adapted well but there were concerns; e.g. chemotherapy spillage, PICC-line malfunctioning and the PICC-line alerting outsiders to the participant’s illness. There was unease around the expected level of involvement in terms of PICC-line. For example *“I wasn’t too happy about them asking her to get involved if there’s a problem with the line and I said ‘well wait a wee minute here. I am not putting that sort of responsibility on to my wife...is it going to turn into septicaemia or phlebitis or thrombosis because that’s the actual words they used...frightening names”*. P4

Information giving to PICC-line patients appeared to be the greatest challenge. Although participants felt well supported by staff, they struggled with the volume and nature of the information. Information was described as *“unhelpful, excessive”* and at times, *“frightening.”* Nevertheless, the advantages of having a PICC-line outweighed the disadvantages for most and the general consensus was of adaptation and acceptance. *“I know I’m dying.....but this*

*line (PICC) has meant that I've not needed to be away from the house overnight, leaving my own bed and that's been great". P10*

## **Results: Phase 2**

### **Response rate**

Of the 69 patients approached to take part in Phase 2, three refused. Of the 66 who agreed to take part, 62 completed the questionnaire giving a response rate of 93.9%.

### **Patient profile**

The 'typical' patient was male, aged 60-79 years, lived within 20 miles of the Chemotherapy Day Unit, found it easy to access the unit, did not know what a PICC-line was prior to insertion and usually had had only one PICC-line insertion for the current course of treatment (Table 1).

### **Impact on daily life**

A majority of patients (Table 2) found showering (CI: 41%, 72%) and hair washing (CI: 44%, 70%) 'a lot more difficult' with a PICC-line in situ. However a sizeable minority of patients also found bathing (CI 30%, 58%) and sleeping (CI: 16%, 40%) problematic. Nevertheless the majority of patients were able to maintain daily living activities (DLAs) satisfactorily.

### **Responsibility/coping at home**

As noted earlier, the questionnaire presented respondents with a series of statements on responsibility and coping, information giving and acceptance. In response to each set of statements, the same data analysis procedure was employed; that is a 95% confidence interval [CI] was calculated between those who 'agreed/strongly agreed' with each statement and those who 'disagreed/disagreed strongly'. If the resulting CI was entirely positive, then a clear majority of patients 'agreed' with the statement. If the CI was entirely negative, then a clear majority 'disagreed' with the statement. This procedure allowed us to understand which statements had the unequivocal support [or not] of the majority of our PICC-line patients.

There was strong evidence (Table 3) that our patients were much more likely to feel well-supported during PICC-line treatment than not (CI: 83%, 100%); were happy to take responsibility for their PICC-line (CI: 26%, 66%); felt a PICC-line contributed to their maintaining independence (CI: 42%, 78%); that PICC-lines made chemotherapy easier to receive (CI: 55%, 83%); and were relaxed at home with a line (CI: 35%, 74%). They also strongly preferred to receive out-patient treatment (CI: -91%, -63%).

However the positive benefits were tinged with some concerns. For example, while a significantly larger population proportion was likely to deny that chemotherapy via a PICC-line, presented extra worries (CI: 11%, 56%), equally there were acknowledged worries about potential chemotherapy spillage (CI: 33%, 76%), about the possible malfunction of their PICC-line (CI: 11%, 59%); and/or the dislodging of a PICC-line from situ (CI: 3%, 49%); and many patients felt their friends and families worried about the PICC-line (CI: 11%; 58%).

### **Information giving**

Again, the same statistical procedure described earlier was applied to information statements. Table 4 shows that overall a significant majority of MdG PICC-line patients wanted as much information as possible about their situation (CI: 38%, 77%) and received optimal information (CI: 37%, 73%) but nonetheless many had difficulty remembering the information (CI: 32%, 74%) and some found it 'scary' (CI: 19%, 64%). A small majority thought too much information was a 'bad thing' (CI: 0.03%, 45%).

It was interesting to note patient views on doctors' and nurses' information giving (Table 4). Given that patients wanted to know as much about their situation as possible, we were somewhat surprised by the lack of a clear-cut position from patients about being told everything about their PICC-line. Rather there were almost equal numbers 'agreeing' and 'disagreeing' as well as those declaring no view at all (CI: -27%, 20%). Ambivalence was also seen on the part of patients (CI: -26%, 23%) as to why nurses and doctors provide full information - 'it is just because they feel they have to'. While there were no statistical differences between patients who felt they had been given a choice to have a PICC-line and those who weren't; or between those who knew what to expect from a PICC-line insertion and those who didn't, it is striking that many patients felt unprepared (n=32) or felt they had been given little choice on the treatment mode (n=32).

### **Adaptation/acceptance**

Table 5 provides strong evidence that a significant majority saw their PICC-line as beneficial with advantages outweighing disadvantages (CI: 72%, 92%); would recommend one to others (CI: 72%, 92%); and although more help was needed at the beginning (CI: 42%, 77%), adapted positively to the line (CI: 56%, 89%). Only a minority found the experience frightening (CI: -56%, -11) and struggled to adapt to life with a PICC-line (CI: -68%, -25%). However the degree of comfort patients felt about strangers knowing they had a PICC-line (CI: -42%, 6%) or in showing it to

others (CI: -19%, 29%) indicated again a considerable ambivalence with a sizeable minority thinking it best to avoid crowds with a PICC-line in situ (CI: -9%, 35%).

Additional written comments were provided by 13 respondents but these tended to be idiosyncratic complaints around car parking or reiteration of the interviews' thematic analysis and questionnaire results.

## **Discussion**

### **Living with a PICC-line**

In this study, only minimal difficulty with most DLAs was reported by most patients in line with Gabriel (2003; 2000) who found that lifestyle was relatively unaffected by a PICC-line. Like Oakley et al (2000) who reported that patients experienced most difficulty with bathing and sleeping but that these diminished with time, the patients in this study experienced difficulties with showering, hair washing, bathing and sleeping. These findings are important as they affect our sense of well-being and therefore it was clear that more, practical information related to bathing/showering and sleeping with a PICC-line was needed by these patients.

Oakley et al (2000) also reported that half of their study patients experienced difficulty in dressing but this finding was not upheld in our study. It may be that as the patients in this study had the PICC-line in situ for a mean of 11 weeks at questionnaire completion compared with the four weeks in Oakley et al's study, that any initial difficulties with dressing were resolved with patients learning how to manage effectively over time.

### **Responsibility for the PICC-line**

In this study, participants generally coped well at home with their PICC-lines and most appeared happy to take on the additional responsibility. There was an acceptance that having a PICC-line had a major impact on their daily lives but the bonus was not being hospitalised to receive chemotherapy. This is in keeping with Chernecky (2001) who found that the advantages associated with a CVAD in the home setting more than compensated for the difficulties.

Most patients in this study felt well supported and able to cope at home with the PICC-line. Therefore despite their fears, generally patients were happy to take on the added responsibility associated with the PICC-line. Furthermore, there was strong evidence that

patients did not want to be hospitalised for chemotherapy treatment which may have influenced their acceptance to take on the responsibility for the PICC-line. However a desire to be treated away from the hospital setting does not necessarily imply a willingness or competence to take on board the added responsibility necessary. This study showed that in keeping with AETMIS (2004), it could not be assumed that all patients had the confidence to cope at home with a PICC-line.

Despite the positive views towards coping at home with a PICC-line, concerns continued related to chemotherapy spillage, malfunction of the PICC-line or the PICC-line falling out. Patients felt their families and friends worried about the PICC-line. However when given the opportunity to provide additional comments in the questionnaire, nothing was said. Nevertheless friends and family may require some assistance to aid their coping.

### **Information giving**

This study suggests participants found it difficult to cope with the amount of information given to them around the time of PICC-line insertion and some information was frightening and/or unhelpful. This is not surprising when one considers the information these patients require in what could only be a stressful situation: e.g. details of cancer recurrence, prognostic outlook, schedule of appointments, chemotherapy regimen and side effect management and PICC-line information.

Although the patients in this study reported a high information need, most also wished to avoid excessive information about what might go wrong. In line with others who found patients felt unprepared for the insertion experience despite the information given pre-insertion (Oakley et al 2000), the patients in this study also felt likewise. This suggests that the type and timing of information is still not all it could be despite continuing interest in improving information quality (Skalla et al 2004, Elf & Wikblad 2001, McCaughan & Thompson 2000, Sitzia & Wood 1998). New and more efficient ways of giving patients information that is complex and voluminous, are required if patients' needs are to be adequately addressed.

### **Adapting to the PICC-line**

The majority of participants adapted well to the experience of living with a PICC-line in keeping with earlier studies (Gabriel 2003, 2000, Oakley et al 2000) and stated that they would recommend a PICC-line to other patients. The potential advantages associated with a PICC-line appeared critical in helping patients accept ambulatory chemotherapy. Questionnaire results showed that the majority feared needles but that the PICC-line with its

infusion pump made chemotherapy administration easier. Indeed, the reduction in the number of venous cannulations for chemotherapy administration is one of the most prominent positive indicators for acceptance of a PICC-line or other CVADs (AETMIS 2004, Chernecky 2001). Many cancer patients require intensive and/or lengthy chemotherapy regimens using irritating agents that can irreparably damage peripheral venous access and may have or develop needle phobia (Ost 1992). Therefore this advantage alone may merit the insertion of a PICC-line for some patients.

It was also evident that despite initial difficulties, patients felt the benefits of a PICC-line outweighed the drawbacks. But more help was required at the start of the PICC-line experience which again has implications for the support of PICC-line patients.

Our findings on what impact a PICC-line has on patients' body image were inconclusive. It appeared that for some patients, the PICC-line represented a 'badge' of illness that they were unhappy to reveal whilst others had no such concerns. As questionnaire data collection was conducted during the winter and spring, most participants had not experienced living with a PICC-line during the summer. Therefore patients may have been less conscious of PICC-line/pump visibility as it would have been camouflaged by winter clothing. It is probable that more patients would have reported unease if data collection had taken place during warmer weather.

Many participants needlessly perceived they must avoid crowded areas such as shopping centres for fear of the PICC-line being damaged, in keeping with Oakley et al's study (2000). Given these patients had incurable cancer and did not have the promise of future health to look forward to, this is a concern as it could potentially lead to patients withdrawing from social situations they may have otherwise enjoyed.

### **Study limitations**

The main limitation is that the study was conducted in only one setting. All consecutive admissions during the data collection period were reviewed for study admission. Arguably the sample is representative of our sampling frame; that is MdG patients receiving ambulatory chemotherapy in the oncology unit where data collection took place. The questionnaire satisfied the conditions for content and face validity but nevertheless was designed specifically for this study and not subject to test-retest measurement.

## **Conclusions.**

The study explored the views and experiences of patients receiving ambulatory MdG chemotherapy via a PICC-line. The results demonstrate that the majority held favourable views towards having a PICC-line and adapted well to the experience. The main challenges centred on showering, bathing, hair washing and sleeping and worries continued during the treatment experience but there were others related to the provision of optimal information as there were some reports that information was unhelpful or scary.

The value of this study was its ability to document specific difficulties faced by patients with PICC lines in the home environment in relation to a number of key areas and it is one of only a handful of studies which have examined the impact of a PICC line on ambulatory patients despite the huge increase in both the use of PICC lines and ambulatory chemotherapy.

We would argue that although this was not a longitudinal study, it appeared that patients' perceptions of problems with PICC-lines, lessened with time. For example 'time' was mentioned frequently in interviews leading to the identified theme of "adaptation/acceptance". Questionnaire statements 'having a PICC line gets easier the longer you have it' and 'patients with PICC lines need more help at the beginning' had strong majority agreement. Considering the interview findings with questionnaire responses, suggests that patients did find problems diminished with time as they adapted to having the PICC line in situ.

In considering the implications of this study for future practice, we would recommend that (i) current information given to patients requiring a PICC-line should be reviewed locally and different methods of providing information explored; (ii) patients should be assessed formally as to their ability to cope at home with a PICC-line; (iii) ways of providing maximum support at the beginning of the PICC-line experience should be explored; (iv) PICC-lines should be considered for use in more chemotherapy patients; and finally (v) further research should be carried out into the specific needs of different groups of PICC-line patients.

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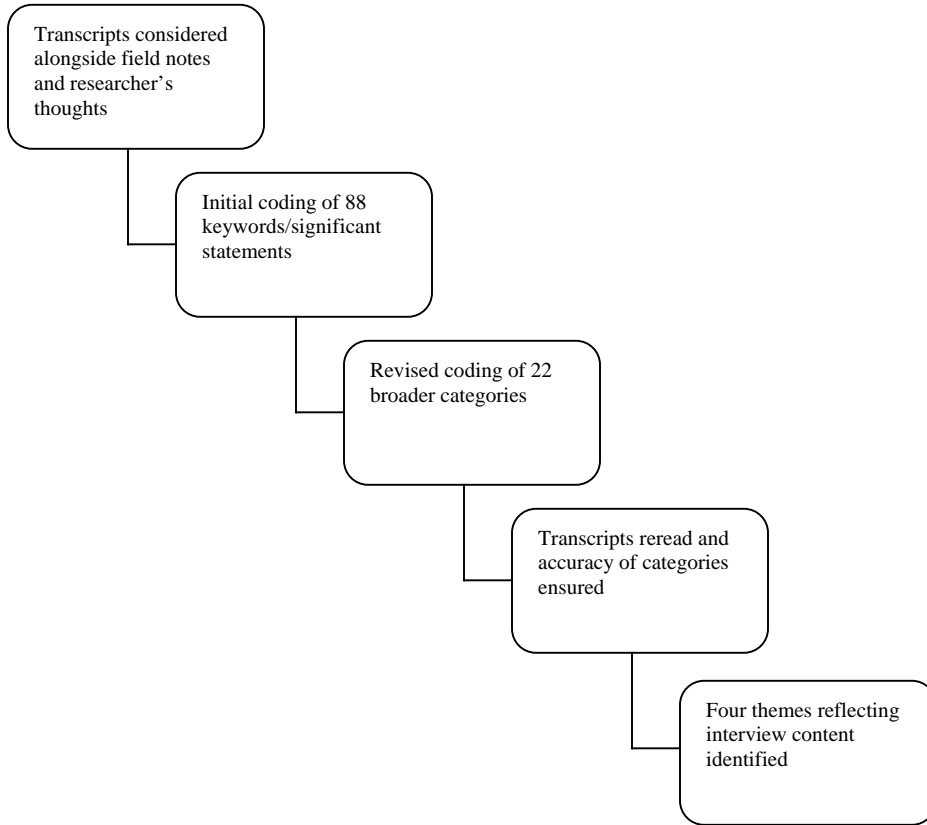
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**Figure 1** Phase 1 data analysis thematic analysis steps



**Table 1**      **Phase 2 patient profile**

	<b>n (%)</b>
18 - 59 years	20 (32.3%)
60 - 79 years	39 (62.9%)
> 79 years	3 (4.8%)
Male	34 (54.8%)
Female	28 (45.2%)
< 20 miles from home to chemotherapy day unit	34 (54.8%)
> 20 miles from home to chemotherapy day unit	28 (45.2%)
Easy to get from home to chemotherapy day unit	45 (72.6%)
Difficult to get from home to chemotherapy day unit	17 (27.4%)
Knew what a PICC line was prior to insertion	5 (8.1%)
Didn't know what a PICC line was prior to insertion	49 (79%)
Can't remember	8 (12.9%)
1 PICC line required for this course of treatment	47 (75.8%)
2 PICC lines required for this course of treatment	14 (22.6%)
>2 PICC lines required for this course of treatment	1 (1.6%)

**Table 2 Phase 2 comparison of pre and post PICC line insertion daily life activity**

Daily life activity	Number performing activity pre-PICC line insertion n=62	Number reporting 'a lot more difficulty' post-PICC line insertion n=62	95% CI [for the population proportion experiencing 'a lot more difficulty' post-PICC line insertion]
Showering	44	25 (56.8%)	(41%, 72%)*
Washing hair	61	35 (57.3%)	(44%, 70%)*
Bathing	59	26 (44.0%)	(30%, 58%)*
Sleeping	62	17 (27.4%)	(16%, 40%)*
Shopping	62	9 (14.5%)	(7%, 26%)
Dressing	62	8 (12.9%)	(5%, 24%)
Hobbies	44	5 (11.4%)	(4%, 24%)
Driving	41	4 (9.8%)	(3%, 23%)
Washing myself	62	6 (9.7%)	(4%, 20%)
Childcare	25	1 (4.0%)	(0.1%, 20%)
Cooking	54	4 (7.4%)	(2%, 18%)
Housework	58	4 (6.9%)	(2%, 17%)
Relaxing	60	2 (3.3%)	(0.4%, 11%)

\* indicates activity is a 'lot more difficult' post-PICC line insertion

**Table 3 Differences in Phase 2 patients' views on responsibility and coping at home with a PICC line**

Statement	A/SA n=62	D/SD n=62	95% CI <sup>▲</sup>
There is plenty of help and support for people with PICC lines	59	27	<b>(83%, 100%)</b>
I worry about the chemotherapy spilling	48	14	<b>(33%, 76%)</b>
The PICC line has made my chemotherapy easier to get	46	3	<b>(55%, 83%)</b>
Having a PICC line gives me independence	45	8	<b>(42%, 78%)</b>
I am relaxed when I am at home with my PICC line	45	11	<b>(35%, 74%)</b>
I worry that things could go wrong with my PICC line	42	20	<b>(11%, 59%)</b>
I am happy to take responsibility for my PICC line*	39	11	<b>(26%, 66%)</b>
My family/friends worry about my PICC line*	39	18	<b>(11%, 58%)</b>
I worry that the PICC line will fall out	38	22	<b>(1%, 50%)</b>
PICC lines give me extra worries when getting chemotherapy	18	39	<b>(-56%, -11%)</b>
My life is restricted because of the PICC line	12	41	<b>(-67%, -26%)</b>
I would have preferred to get my chemotherapy in hospital	4	52	<b>(-91%, -63%)</b>

<sup>▲</sup>95% confidence intervals for population proportion of those who agree/strongly agree [A/SA] minus population proportion of those who disagree/strongly disagree [D/SD] for responsibility/coping statements.

CIs in bold indicate a significant majority either agreeing (positive) or disagreeing (negative) with the statement.

\*missing data = 1

**Table 4 Differences between MdG patients' views on information giving**

<b>Statement</b>	<b>A/SA n=62</b>	<b>D/SD n=62</b>	<b>95% CI<sup>▲</sup></b>
I like to know as much as possible about what is happening to me	47	11	<b>(38%, 77%)</b>
It is impossible to remember all the information you are given	47	14	<b>(32%, 74%)</b>
I had all the information I needed to cope with my PICC line at home	45	14	<b>(29%, 71%)</b>
Some of the information I was given about my PICC line was quite scary	43	17	<b>(19%, 64%)</b>
The information I was given about my PICC line was just right	42	8	<b>(37%, 73%)</b>
I do not like to be told too much about things that could go wrong	34	16	<b>(7%, 50%)</b>
Too much information is a bad thing	33	19	<b>(0.03%, 45%)</b>
Doctors and nurses tell you things just because they feel they have to	28	29	(-26%, 23%)
Patients should be told absolutely everything about their PICC line	26	28	(-27%, 20%)
I knew what to expect when the PICC line was put in	22	32	(-39%, 7%)
I was given the choice to have a PICC line or not	18	26	(-34%, 8%)

▲95% confidence intervals for population proportion of those who agree/strongly agree [A/SA] minus population proportion of those who disagree/strongly disagree [D/SD] for responsibility/coping statements.

CIs in bold indicate a significant majority either agreeing (positive) or disagreeing (negative) with the statement.



**Table 5 Differences between MdG patients' views on adaptation/acceptance**

<b>Statement</b>	<b>A/SA n=62</b>	<b>D/SD n=62</b>	<b>95% CI<sup>▲</sup></b>
Having a PICC line gets easier the longer you have it	52	7	<b>(56%, 89%)</b>
The good things about a PICC line are more than the bad*	50	0	<b>(72%, 92%)</b>
I would recommend a PICC line to other patients**	49	0	<b>(72%, 92%)</b>
Patients with PICC lines need more help at the beginning	44	7	<b>(42%, 77%)</b>
I will do whatever it takes to get my chemotherapy	43	15	<b>(23%, 67%)</b>
I am frightened of needles	40	21	<b>(6%, 54%)</b>
I am happy to show my PICC line to anyone	30	27	(-19%, 29%)
It is best to avoid crowds if you have a PICC line	29	21	(-9%, 35%)
It bothers me if strangers see my PICC line	23	34	(-42%, 6%)
Having a PICC line in is a frightening experience	17	38	<b>(-56%, -11%)</b>
Having a PICC line is not the sort of thing you ever get used to	14	43	<b>(-68%, -25%)</b>
Having a PICC line is more trouble than it is worth*	2	49	<b>(-90%, -65%)</b>

<sup>▲</sup>95% confidence intervals for population proportion of those who agree/strongly agree [A/SA] minus population proportion of those who disagree/strongly disagree [D/SD] for responsibility/coping statements.

CIs in bold indicate a significant majority either agreeing (positive) or disagreeing (negative) with the statement.

\*missing data = 1: \*\*missing data = 2