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Community-based Intravenous Treatment and Central Venous Access Devices: A Scoping Review of the Consumer and Caregiver Experience, Information Preferences, and Supportive Care Needs

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ABSTRACT

Purpose: Map existing research and describe the consumer/caregiver experience of community-based intravenous treatment, central venous access devices (CVADs), supportive care needs, and information preferences.

Design: Scoping review.

Methods: Five databases (Joanna Briggs Institute, Cochrane library, Emcare, Embase, and Medline) were searched. Screening and data extraction were performed independently by two reviewers.

Findings: Forty-eight studies were included

Conclusions: Although community-based intravenous treatment and CVADs have a significant impact on consumers and caregivers, there is scant research on their supportive care needs and information preferences.

Clinical Evidence: Some consumers and caregivers may require additional support while undergoing community-based intravenous treatment.

Introduction

Intravenous treatment, the administration of medications and blood products directly into the vein is an integral part of contemporary health care. A central venous access device (CVAD) such as a peripherally inserted central catheter (PICC) or a totally implanted venous access device (TIVAD) or “port” is inserted to enable treatment. CVADs offer reliable access for medium/long term administration of antibiotics or anticancer treatments and frequent blood sampling (Moureau & Chopra, 2016).

The provision of intravenous treatment in the community setting is an increasingly common treatment model (Montalto et al., 2020). The use of this model has grown markedly in the last decade, with the recent COVID 19 pandemics further increasing demand (Dickson, 2020). Short/medium term infections as well as many types of cancer are commonly treated with intravenous infusions in the community (Evans et al., 2016; Mitchell et al., 2017). Various models of community-based intravenous treatment are used in clinical practice. Some people undergo all of their treatment in the home setting (nurse or self-administered), and others have a combination of home/outpatient department treatment.

Intravenous treatment in the community setting is associated with the risk of adverse events. Up to 30% of the consumers receiving outpatient parenteral antimicrobial therapy (OPAT) develop an adverse event due to the antibiotic (Sriskandarajah et al., 2018). CVAD complications

in the community are similar to rates in acute care facilities. Between 6% and 25% of consumers with a PICC undergoing community-based antibiotic or chemotherapy treatment experience a complication (Bertoglio et al., 2016; Cotogni et al., 2015; Kang et al., 2017; Marsh et al., 2020; Sriskandarajah et al., 2020). These include serious complications such as deep vein thrombosis.

Community-based intravenous treatment may have a significant impact on the consumer and caregiver. Treatment outside of hospital requires consumers and caregivers to understand often quite complex information and assume increased responsibility for their care. It is important that consumers and caregivers understand CVAD information as they may be required to identify and escalate CVAD associated adverse events independently at home. Major adjustments to daily life are necessary to adapt to living with a CVAD. Individual studies have indicated that a CVAD may have physical, social, and psychological effects (Paras-Bravo et al., 2018; Ritchie et al., 2015). All of these factors indicate that consumers (and their caregivers) may have unmet supportive care needs.

An understanding of the consumer and caregiver experience, supportive care needs, and information preferences would provide clinicians valuable insight into supports that may be introduced to provide safe, quality health care in the community. Additionally, it is important to map existing research to identify knowledge gaps to inform future research and clinical practice. Yet, to our knowledge, a scoping review has not previously been carried out in this area. Hence, the aim of this scoping review was to map existing research and describe the experience of consumers and caregivers undergoing community-based intravenous treatment. This included the consumer and caregiver perception of the clinical model and CVADs used to provide treatment, supportive care needs, and information preferences.

Method

A scoping review method that allows rapid summation of research and identification of gaps in knowledge was used. This scoping review follows the frameworks proposed by Arksey and O'Malley (2005) and the Joanna Briggs Institute (JBI) (Peters et al., 2020) and is reported in accordance with the Extended Preferred Reporting Items for Systematic Reviews and Meta-Analyses Statement for Scoping Reviews (PRISMA-ScR) (Tricco et al., 2018). The following steps were undertaken: 1. Identify the research questions; 2. Identify relevant studies; 3. Select studies for inclusion; 4. Sort and collate data; and 5. Summarize and report results.

For the purpose of this review, community-based intravenous treatment was defined as intravenous treatment occurring in a primary place of residence (private dwelling or residential care facility) and/or outpatient/ambulatory care facility. A caregiver was considered anyone who provided unpaid assistance for a health consumer regardless of relationship (relative or friend) (Kent et al., 2019).

Identify the research questions

The following research questions were used to guide the search for this scoping review.

- (1) What is the consumer and caregiver experience of community-based intravenous treatment reported in the peer-reviewed literature, including their experience of CVADs and auxiliary products used to provide treatment?
- (2) What are the supportive care needs and information preferences of these consumers and/or their caregivers as reported in the peer-reviewed literature?

Table 1. Inclusion/exclusion criteria.

Inclusion criteria
<ul style="list-style-type: none"> • Original qualitative, quantitative, or mixed method peer-reviewed research was published after 2000, in English with adult participants (18 years and over) that reports the experience of consumers with cancer or infection and/or caregivers undergoing community-based intravenous treatment. Including their experience of central venous access devices (CVADs) and auxiliary products, supportive care needs, and information preferences • Intravenous treatment (infusion or bolus) – antibiotics, chemotherapy, and other cancer treatment, blood products • Self or nurse administered • Community-based setting, including residential home, outpatient/ambulatory care centers, general practice (GP) clinic, and residential care facility
Exclusion criteria
<ul style="list-style-type: none"> • Focus on general needs or experience rather than community-based intravenous treatment • Focus on medication side effects, such as chemotherapy side effects • Consumer and/or caregivers experience explored in limited depth • Intravenous treatment for life-long treatment • Consumers at the end-stage of their disease undergoing palliative care management • Focus on CVAD insertion • Short reports, case studies, conference abstracts, systematic reviews/review articles, or study protocols that lacked outcomes • Mixed pediatric/adult population where results are not reported separately • Experience of intravenous treatment not reported separately

Identify relevant studies

Articles were included that focused on the experience of health consumers undergoing community-based intravenous treatment for cancer or infection and their caregivers based on criteria outlined in Table 1. Results were limited to the English language from the year 2000 onwards.

Select studies for inclusion

Search strategy

The search strategy was designed with a specialist health sciences research librarian, and the search was initially conducted November 1, 2019. The search was repeated on September 2, 2021. Keywords were developed based on previous research and exploration of medical subject headings. The following databases and search engine were searched: Joanna Briggs Institute, Cochrane library, Emcare, Embase, Medline, and Google Scholar. The reference lists of identified studies were hand searched for additional relevant studies.

Selecting the literature

Article abstracts were imported into EndNote™ (Clarivate Analytics, London, United Kingdom) and transferred to Covidence™ (Veritas Health Innovation, Melbourne, Victoria, Australia) for screening purposes. Two authors reviewed each abstract independently according to the inclusion criteria (RS QX, AU, or NC). Where disagreements occurred, a third author acted as an arbiter.

Charting, collating, and summarizing the information

Study information and the treatment setting/model was extracted from each article. Included articles were divided according to diagnostic group for data extraction as it was thought that the experience and needs of consumers/caregivers may differ according to diagnosis. Two authors (RS and QX) independently extracted quantitative and qualitative findings from articles that was checked by a third author against the full text to ensure that all results were presented. Authors (RS and QX) independently grouped similar codes to form a synthesis for each diagnostic group. Any disagreements were discussed until consensus was achieved. Authors were mindful of the need to stay close to the original research findings rather than try to interpret findings (Peters et al., 2020).

Results

Selection of studies

The modified Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow chart (Tricco et al., 2018; Figure 1) presents the study selection process.

Findings

Forty-eight studies met the inclusion criteria (Table 2). Most studies were set in the UK (n = 16), followed by the USA (n = 8), Sweden (n = 4), Canada (n = 3), Germany (n = 2), France (n = 2), and South Korea (n = 2). The remaining studies were set in Australia, China, Switzerland, Denmark, The Netherlands, Spain, Italy, Ireland, New Zealand, Belgium (one study each). One study was set in both the UK and Sweden. Study location, information, treatment setting/model, and CVAD/auxiliary equipment details are reported in S1 (Table 3).

Population

There were 33 studies that included participants with cancer, 13 study participants with an infection and two studies that included participants with cancer or an infection. As the latter studies that included consumers with cancer or an infection used a qualitative design, the results could not be separated by diagnostic groups and hence are reported separately.

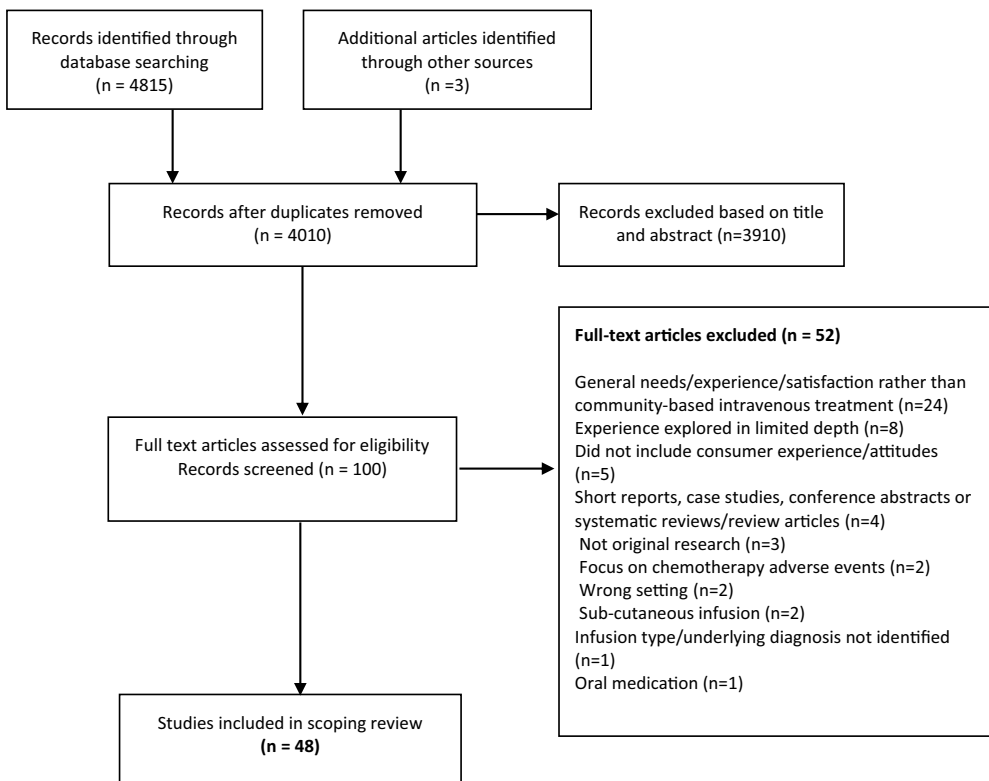


Figure 1. Modified PRISMA flow diagram for article selection.

Table 2. Study population and elements of research questions addressed in the studies.

Author, year	Cancer Diagnosis	Infection diagnosis	Caregivers	Experience of community- based intravenous treatment	Experience of CVAD/ auxiliary equipment	Supportive care needs	Information preferences
(Ademokun et al., 2005)	x			x			
(Ai et al., 2021)	x				x		
(Alpenberg et al., 2015)	x			x	x		
(Anderson et al., 2003)	x		x	x			
(Bakker et al., 2001)	x			x			
(Berrevoets et al., 2018)		x	x	x	x	x	x
(Brown et al., 2018)	x	x			x		
(Chernecky, 2001)	x				x		
(Comerford & Shah, 2018)	x			x		x	
(Corrie et al., 2013)	x			x			
(Crisp et al., 2014)	x			x			
(Goossens et al., 2005)	x				x		
(Hall & Lloyd, 2008)	x			x			
(Italiano et al., 2006)	x			x			
(Johansson et al., 2001)	x			x	x		
(Johansson et al., 2005)	x			x	x		x
(Joo et al., 2011)	x			x	x		
(Källenius Edström et al., 2016)	x				x		
(Keller et al., 2019a) (AJMQ)		x	x	x	x		x
(Keller et al., 2019b) (Joint Commission)		x	x	x			
(Keller et al., 2019) (AJIC)		x	x	x	x		
(Keller et al., 2020)		x	x	x	x		
(Kelly & Snowden, 2021)	x				x		
(Keshvani et al., 2019)	x			x			
(Kieran et al., 2009)		x		x			
(Kreis et al., 2007)	x				x		
(Kumari et al., 2018)		x		x	x		
(Lal et al., 2015)	x			x			
(Luthi et al., 2012)	x		x	x	x		
(Mansour et al., 2019)		x		x	x		
(Minichsdorfer et al., 2016)	x				x		
(Mitchell et al., 2017)	x		x	x			
(Moller & Adamsen, 2010)	x				x		x
(Molloy et al., 2008)	x		x		x		
(Oakley et al., 2000)	x				x		x
(Pace et al., 2009)	x			x			
(Papaioannou et al., 2018)		x	x	x			
(Paras-Bravo et al., 2018)	x				x		
(Park & Lee, 2020)	x				x		
(Piredda et al., 2016)	x				x		x

(Continued)

Table 2. (Continued).

Author, year	Cancer Diagnosis	Infection diagnosis	Caregivers	Experience of community-based intravenous treatment	Experience of CVAD/ auxiliary equipment	Supportive care needs	Information preferences
(Ritchie et al., 2015)	x				x		
(Rowe et al., 2002)	x			x	x		
(Ryan et al., 2019)	x				x		
(Saillen et al., 2017)		x		x	x		
(Sharp et al., 2014)	x	x		x	x		
(Stephens, 2013)		x		x			
(Tonna et al., 2019)		x		x			
(Twiddy et al., 2018)		x		x	x		

CVAD = central venous access device

Study design

There were 27 studies that used a qualitative methodology to explore the consumer and/or caregiver experience. With 17 qualitative studies including consumers with cancer, 9 consumers with an infection and one study with both consumer groups. The remainder of the studies (n = 21) surveyed consumers to determine consumer satisfaction, with nine studies allowing free-text responses in the survey.

Consumer and caregiver experience of community-based intravenous treatment

There were 32 studies that reported the consumer or caregiver experience of the clinical model used for community-based intravenous treatment (Table 2). A synthesis of their experience is presented in S1 (Table 4).

Caregivers of consumers with cancer

Of these studies, three investigated the experience of caregivers of an individual with cancer undergoing community-based intravenous treatment (Anderson et al., 2003; Luthi et al., 2012; Mitchell, 2013). Caregivers described that they were in partnership with consumers while undergoing community-based intravenous treatment. Home treatment was especially appreciated as there were psychological and resource benefits for the whole family. However, home treatment had a negative impact for some caregivers. They reported fatigue, and challenges managing clinical care and the psychological state of the consumer (S1 Table 4).

Consumers with cancer

There were 18 studies that reported the experience of community-based intravenous treatment for consumers with cancer (Table 2). Consumers reported the experience of community-based intravenous treatment in terms of continuing usual life, the impact of treatment on family resources (travel/waiting/cost), psychological impact, safety, privacy, information/adaptation, and their perception of care and clinician competence (S1 Table 4).

Caregivers of consumers with an infection

There were six studies that included caregivers of consumers with an infection undergoing community-based intravenous treatment. However, the caregiver experience/attitudes were not reported in four of these studies (Keller et al., 2019a, 2019b, 2019, 2020). The remaining two studies reported the caregiver experience of consumers receiving treatment in a residential aged care facility (Papaioannou et al., 2018) or at home (Berrevoets et al., 2018). Caregivers identified that intravenous treatment provided in a residential care facility was convenient, less burdensome, and safer for consumers. For those undergoing home treatment, caregivers identified that they wanted to be included in the pre-discharge processes, including information sessions and decision-making (S1 Table 4).

Consumers with an infection

There were 13 studies that investigated the experience of consumers with infection undergoing community-based intravenous treatment (Table 2). Consumers reported their experience in the context of adaptation and continuing life, the impact on self, their experience and perception of care, information/learning/knowledge and safety (S1 Table 4).

One study was identified which included individuals with cancer or an infection (Sharp et al., 2014). The authors identified that community-based treatment enabled continuation of life and work, leisure, exercise, and paid employment. However, consumers found waiting for the home nurse to disconnect the infusion restricted their daily activities.

Consumer and caregiver experience of central vascular access devices (CVADs) and auxiliary products

There were 31 studies that reported the consumer or caregiver experience of a CVAD or auxiliary products (Table 2). A synthesis of their experience of a CVAD or auxiliary products is presented in S1 (Table 5).

Caregivers

While six studies included caregivers, none reported their direct experience of providing support for a consumer with a CVAD (Berrevoets et al., 2018; Keller et al., 2019a, 2019, 2020; Luthi et al., 2012; Molloy et al., 2008). Two studies reported the perception of consumers with cancer about the effect of the CVAD on caregivers (Luthi et al., 2012; Molloy et al., 2008). Two studies included caregivers of consumers with an infection who were present during home visits, but they were not asked to describe their experience (Keller et al., 2019a, 2019) and two studies, included caregivers in focus groups or interviews, however, their experience was not reported separately (Berrevoets et al., 2018; Keller et al., 2020).

Consumers with cancer

There were 21 studies that explored the experience of a CVAD or auxiliary equipment in consumers with cancer (Table 2). Of these, most examined the consumer experience of a TIVAD or PICC and four studies included the consumer experience of auxiliary equipment (S1 Table 3). Consumers reported the experience of a CVAD in terms of discomfort, the impact of the CVAD psychologically and on family resources, hiding the CVAD, taking responsibility for care of the CVAD, reducing venepuncture, knowledge/understanding, adverse events, and their perception of care (S1 Table 5).

Consumers with an infection

There were 8 studies identified that reported the experience of a CVAD for consumers with an infection (Table 2). In most studies, there were a mixture of CVADs, such as PICCs and tunneled catheters (S1 Table 3). Consumers reported their experience in the context of adaptation, information, understanding, and knowledge, their perception of clinician knowledge and their experience of adverse events (S1 Table 5).

There were two studies that included participants with cancer or an infection that reported the consumer experience of a CVAD and/or auxiliary equipment (Brown et al., 2018; Sharp et al., 2014). One study examined the consumer experience of a PICC (Sharp et al., 2014) and the other included consumers with PICCs (some TIVADs) but focused on the experience of self-administering with a 'smart' pump (Brown et al., 2018). In these studies, consumers described their experience in the context of understanding information, adaptation, attitude toward the CVAD and adverse events (S1 Table 5).

Supportive care needs of consumers and/or their caregivers

No studies were identified that examined the supportive care needs of caregivers of consumers with an infection or cancer undergoing community-based intravenous treatment.

Two studies examined the supportive care needs of consumers with an infection or cancer receiving community-based intravenous treatment (Berrevoets et al., 2018; Comerford & Shah, 2018). Berrevoets et al. (2018) examined the experience of consumers with an infection undergoing OPAT with a PICC and used the Picker principles of patient-centered care framework to categorize the findings into needs. This framework includes access to care; information, communication, and education; respect for patient values, preferences, and needs; physical comfort; coordination and integration of care; emotional support and alleviation of fear and anxiety; involvement of family and friends and continuity and transition. Safety and freedom were especially important components to ensure quality care (Berrevoets et al., 2018). One study investigated the supportive care needs of consumers with cancer undergoing community-based intravenous treatment with a PICC (Comerford & Shah, 2018). In this survey, nearly all consumers indicated that their emotional, practical, psychological, and spiritual needs were met.

Information preferences of consumers and caregivers undergoing community-based intravenous treatment

There were no studies identified that examined information preferences of caregivers of consumers undergoing community-based intravenous treatment.

This review identified six studies that examined the consumer preference for information provision (Table 2). Four studies included consumers with cancer (Johansson et al., 2005; Moller & Adamsen, 2010; Oakley et al., 2000; Piredda et al., 2016) and two studies of consumers with an infection (Berrevoets et al., 2018; Keller et al., 2019a). Most studies reported the consumer preference for information about CVADs rather than community-based intravenous treatment generally.

For some consumers with cancer who self-administered at home, the delivery of information about intravenous treatment in the community was not suitable, it was minimal and some preferred education to be provided in group sessions (Johansson et al., 2005). Consumers with a TIVAD indicated that they preferred an information booklet that was evidence-based, written in plain text containing images with information about the TIVAD structure (Piredda et al., 2016). Information about the implantation procedure, management, complication signs, phone contacts in case of problems or questions, and TIVAD removal was perceived as useful for consumers and improved knowledge and reduced anxiety (Piredda et al., 2016). Information format preferences differed which reflected individual learning needs/style for consumers with a PICC, including written, verbal, and tactile learning (Oakley et al., 2000). Some consumers identified it would be beneficial to learn from others who had experienced living with a PICC (Oakley et al., 2000). Consumers who learned to self-manage their CVAD indicated that structured one-on-one training, repetition, written materials and practicing tasks under supervision with feedback was important to become proficient in CVAD care (Moller & Adamsen, 2010).

Consumers with an infection identified that written and oral information should be provided during education about community-based intravenous therapy (Berrevoets et al., 2018). Consumers with an infection self-administering antibiotics at home preferred a formal education session explaining CVAD insertion, care, management of the CVAD during activities of daily living, troubleshooting, and consequences of complications, such as dislodgement and identified that 'teach-back' was a useful method to learn tasks (Keller et al., 2019a).

Discussion

This scoping review aimed to map existing research and describe the experience, information preferences, and supportive care needs of consumers and caregivers undergoing intravenous treatment in the community. During our scope of the literature, we found that most research in this area

has focused on consumers with cancer. However, much of this research was excluded as it examined their overall experience and general needs, or it explored the experience/needs of chemotherapy side-effects. Although there may be some similar concepts, these studies do not allow an understanding of the specific experience and needs of consumers/caregivers undergoing intravenous treatment in the community.

Consumer/caregiver experience

While a variety of perspectives were evident, consumers with an infection or cancer undergoing community-based intravenous treatment reported similar experiences. These included the process of adaptation, continuing usual life, impact of treatment on family resources and self, safety, information/learning, and their perception of care and clinician competence. Comparably, few studies were found that explored the experience of consumers, with an infection undergoing community-based intravenous treatment. Of those articles that included this population, nearly half focused on self-administration of intravenous antibiotics rather than the more common nurse-administered model (Mitchell et al., 2017). This signifies a clear research gap and further research is required to understand the experience of this group of consumers.

Similarly, few studies examined the experience of caregivers of consumers with cancer or an infection undergoing community-based intravenous treatment. The lack of research is most evident in caregivers of individuals with an infection, with only two studies identified (Berrevoets et al., 2018; Papaioannou et al., 2018). Among the studies, one examined the caregiver experience of consumers at a residential care facility, presumed a different experience to caregivers that are expected to manage care at home. Overall, caregivers in this scoping review reported that they formed a partnership with the consumer to manage community-based intravenous treatment. Hence, it was important that they were included in the information/education provided by clinicians. While caregivers indicated that community-based intravenous treatment had benefits for the whole family, they identified challenges with managing clinical care. Caregivers of individuals with cancer have been described as ‘the invisible workforce’ (Sun et al., 2019). Caregivers are expected to provide physical, emotional, and practical support, which is increased when treatment is solely provided at home (Tsianakas et al., 2015). Scant research has investigated the impact of the caregiver role for consumers with infection. While further research is required to understand the caregiver experience fully, these findings do indicate that clinicians should recognize caregivers as important members of the care team. Where appropriate, the community health nurse should include the caregiver when providing care and information. They should also consider additional supports that may be required for the caregiver.

The consumer and caregiver experience of CVADs

We found no published articles about the experience of caregivers regarding CVADs or auxiliary products in the literature. Studies that reported the consumer experience of a CVAD centered on consumers with cancer. Few studies reported the consumer experience of auxiliary devices, such as electronic or elastomeric pumps. It does appear that both the pump and tubing had both psychological (Johansson et al., 2005) and practical consequences (Brown et al., 2018; Johansson et al., 2005; Keshvani et al., 2019; Ryan et al., 2019; Sharp et al., 2014) for some consumers. The pump and tubing made usual activities such as showering challenging, and they avoided public places due to the visibility of these external components.

Consumers with cancer and infection reported similar experiences and attitudes regarding the CVAD. These were framed around concepts, such as adaptation, information provision by clinicians, psychological impact of the CVAD, and fear of adverse events. Consumers valued their CVAD to reduce venepuncture and facilitate treatment. Yet, many faced practical challenges adapting to living with the CVAD. Anecdotally, it appears that most information provided by clinicians focuses on risks associated with insertion for the consent process as well as recognizing and responding to adverse

events. This is understandable; however, it is also important that appropriate practical supports are provided to aid adaptation to improve the consumer experience. Little research has been undertaken in this area; one study set in China investigated the effect of a video containing information about living with a PICC and found no difference in consumer satisfaction (Li et al., 2020). However, the focus of the intervention was procedural information to support the consent process and content was designed by clinicians without input from consumers. Future research could use a co-design approach that includes consumers to ensure that practical supports meet their needs (Castro et al., 2018).

While there were many similar experiences reported by these consumer groups, there were some differences. For example, consumers with cancer described a greater psychological impact from the CVAD. They identified distress associated with living with a foreign device in their body and stigma from the CVAD that led them to hide it from others. This may be due to the cancer diagnosis itself as some consumers reported that the CVAD came to symbolize their diagnosis (Alpenberg et al., 2015). Alternatively, this difference may be because this concept has not been adequately explored in consumers, with an infection undergoing community intravenous treatment with a CVAD. Future research could explore the psychological impact of a CVAD for consumers with an infection to further understand their experience and inform appropriate supports in clinical practice.

Supportive care needs

There were no studies identified in this scoping review that investigated the supportive care needs of caregivers, and only two studies examined the supportive care needs of consumers (Berrevoets et al., 2018; Comerford & Shah, 2018). One study surveyed consumers with cancer to see if their needs were met; however, needs were pre-determined by the researchers rather than consumers (Comerford & Shah, 2018). Another study examined the experience and supportive care needs of consumers undergoing OPAT with a visiting nurse specialist at home (Berrevoets et al., 2018). Berrevoets et al. (2018) used the Picker principles of patient-centered care framework to guide interview questions and to categorize participant experiences into needs. Consumers identified that all of the Picker principles were important for quality community-based intravenous treatment. Hence, needs included emotional support, information provision, and continuity of care. Further research could investigate the supportive care needs of these consumer groups in the aim to develop a needs assessment tool. While numerous tools exist to assess the supportive care needs of consumers with cancer (Wang et al., 2018), these tools are general and may not extract the distinct needs of consumers undergoing intravenous treatment with a CVAD in the community. Furthermore, no tools are available to assess the supportive care needs of consumers with an infection undergoing community-based intravenous treatment.

Information preferences

Scant research has examined consumer preferences for the format that information is provided. Most studies focused on CVAD information preferences and only two studies included consumers with an infection. A variety of preferences were reported, including group sessions as well as written, verbal, and tactile learning. Some consumers identified that learning from other consumers that have lived with a CVAD would be beneficial. It appears that consumer preferences differ, and it may be that these preferences change over time. Further research is required to fully understand the information preferences of consumers undergoing intravenous treatment in the community. Community health nurses should incorporate the assessment of information preferences during community intravenous treatment to meet the information needs of consumers.

Limitations

A scoping review does not include methodological and risk of bias evaluations and hence should not be used to inform clinical decision-making. However, the findings do provide clinicians with an understanding of the experience and preferences of consumers and their caregivers. While a rigorous approach was undertaken in this scoping review, several limitations exist. Only articles written in English were included due to fiscal and time constraints. Articles that included populations that required life-long treatment, such as cystic fibrosis or those at the end-stage of their disease undergoing palliative care management, were excluded. Therefore, these findings may not be relevant to those populations.

Conclusion

Community-based intravenous treatment is an increasingly common clinical model in contemporary health care. Consumers and caregivers appreciate the provision of community-based intravenous treatment. However, this treatment modality and the CVAD used to provide treatment has a significant impact for both consumers and caregivers. There is scant research about the supportive care needs and information preferences of consumers/caregivers undergoing community-based intravenous treatment. Further research is required to ensure safety and improve the experience for consumers and caregivers.

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Appendix

Table 3. Study information, treatment setting/model and central venous access device type

First author, year, location	Study design	Treatment setting	Treatment model (Self or nurse administered)	CVAD/ auxiliary equipment details
Ademokun 2005 UK	n=20/10 Before/after survey	OPD/home	Nurse	
Ai 2021 China	n=11 Qualitative interviews	OPD/ home	Nurse	PICC
Alpenberg 2015 Sweden	n=10 Qualitative interviews	OPD	Nurse	PICC
Anderson 2003 UK	n=24/13 Cohort study/interviews	OPD/ home	Nurse	
Bakker 2001 Canada	n=28 Qualitative interviews	OPD	Nurse	
Berrepoets 2018 Netherlands	n=16/2 Focus groups – consumers/ qualitative interviews - care givers	Inpatient + home	Nurse	PICC
Brown 2018 USA	n= 42 Survey	Home	Self /carer	PICC /TIVAD/Smart pump
Chernecky 2001 Canada	n=24 Survey (free text responses)	OPD	Nurse	TIVAD
Comerford 2018 UK	n=130 Survey (free text responses)	OPD/home/ hotel	Nurse	
Corrie 2013 UK	n=97/11 RCT/survey/ interviews	OPD/home/ GP	Nurse	
Crisp 2014 USA	n=10 interviews	Home	Nurse	
Goossens 2005 Belgium	n= 98 Survey (free text responses)	OPD	Nurse	TIVAD
Hall 2008 UK	n=15 RCT/ interviews	OPD/home	Nurse	
Italiano 2006 France	n=97 Prospective cohort/survey	OPD/home	Nurse	
Johansson 2001 Sweden	n=11 Prospective cohort/survey	Inpatient/ home	Nurse /self	Tunnelled catheter or TIVAD/ Elastomeric infusion pump
Johansson 2005 Sweden	n=21 Qualitative interviews	OPD/home	Nurse /self	Tunnelled catheter or TIVAD/ Elastomeric infusion pump
Joo 2011 South Korea	n=80 Survey	Inpatient/ home	Nurse	TIVAD
Källenius Edstrom 2016 Sweden	n=36 Survey (free text responses)	OPD/home	Not reported	PICC
Keller 2019 (a) (Joint Commission) USA	n=40/20 Interviews/contextual inquiries OPAT tasks	Home	Self	Unidentified CVAD
Keller 2019 (b) (AJMQ) USA	See Keller 2019 (a)	Home	Self	
Keller 2019 (c) (AJIC) USA	n=29/14 consumer interviews/contextual inquiries	Home	Self	
Keller 2020 USA	n=10 Focus groups	Home	Self	Unidentified CVAD
Kelly 2021 UK	n=11 Qualitative interviews	OPD	Nurse	TIVAD, tunnelled catheter or PICC
Keshvani 2019 USA	n=9 Survey (free text responses)	OPD/home	Nurse	Electronic pump
Kieran 2009 Ireland	n=56/12 Cohort/ survey	Home	Self	
Kreis 2006 Germany	n=262 Survey	OPD/home	Not reported	TIVAD
Kumari 2018 New Zealand	n=75 Survey (free text responses)	Inpatient/ home	Nurse /self	PICC (one tunnelled catheter)

(Continued)

Table 3. (Continued).

First author, year, location	Study design	Treatment setting	Treatment model (Self or nurse administered)	CVAD/ auxiliary equipment details
Lal 2015 UK/ Sweden	n=52 Prospective cohort with survey	Inpatient/ home	Nurse	
Luthi 2012 Switzerland	n=17 Cohort/survey (free text responses)	Home	Nurse	TIVAD/ Electronic pump
Mansour 2019 USA	n=98 Survey (free text responses)	Nursing facility /home	Nurse	PICC and other CVADs (CVAD type not identified)
Minichsdorfer 2016 Germany	n=202 Survey	OPD	Nurse	TIVAD
Mitchell 2013 UK	n=20 Qualitative interviews	OPD/ mobile unit	Nurse	
Moller 2010 Denmark	n= 82/18 RCT/ qualitative interviews	OPD/home/ Inpatient	Nurse /self	Tunnelled catheter
Molloy 2008 UK	n=9/62 Qualitative interviews /Survey	OPD	Nurse	PICC
Oakley 2000 UK	n=10 Qualitative interviews	OPD	Nurse	PICC
Pace 2009 UK	n=42 Cross-over randomised study/ qualitative interviews	OPD	Nurse	
Papaioannou 2018 Canada	n=6 Qualitative interviews	Long-term care home	Nurse	
Paras-Bravo 2018 Spain	n=18 Qualitative interviews	OPD	Nurse	PICC
Park 2020 South Korea	n=42 Survey	OPD	Nurse	Unspecified CVC
Piredda 2016 Italy	n=129 Pre and post survey	OPD	Nurse	TIVAD
Ritchie 2015 UK	n=9 Focus group	OPD	Not reported	TIVAD, tunnelled catheter or PICC
Rowe 2002 UK	n = 26 Non-randomised pilot study/survey	Inpatient/ OPD/ home	Nurse /self	Tunnelled catheter
Ryan 2019 UK	n=42 Focus group within multicentre RCT	OPD	Not reported	TIVAD, tunnelled catheter or PICC
Sailien 2017 France	n=112 Survey (free text responses)	OPD/home	Nurse /self	PICC and other CVADs (CVAD type not identified)
Sharp 2014 Australia	n=10 Qualitative interviews	Inpatient/ OPD/ home	Not reported	PICC
Stephens 2013 UK	n=8 Qualitative interviews	Home	Nurse	
Tonna 2019 UK	n=20 Qualitative interviews	OPD	Nurse	
Twiddy 2018 UK	n=32 Qualitative interviews/focus groups	OPD/ home	Nurse /self	Unidentified CVAD

OPD = outpatient department; PICC=peripherally inserted central catheter; CVAD = central venous access device; TIVAD= totally implanted venous access device; RCT= randomised controlled trial.

Table 4. Experience of consumers and/or caregivers undergoing community-based intravenous treatment

Consumers with cancer

Experience of caregivers

Many caregivers preferred home treatment due to reduced distress, travel, waiting, side effects and fatigue (Anderson et al., 2003; Luthi et al., 2012). Other advantages were that it allowed togetherness, autonomy and freedom (Luthi, et al., 2012), some caregivers thought home treatment had advantages for the entire family (Anderson, et al., 2003). Consumers and caregivers reported forming a partnership to undergo outpatient department (OPD) treatment (Mitchell 2013). Although, some caregivers reported that home treatment had disadvantages for the family as they were required to manage adverse events which were thought to be increased at home (Anderson, et al., 2003). Other disadvantages of home care included allowing strangers (clinical staff) into the house which made them feel uncomfortable, the need to be with the consumer constantly, anxiety, fatigue, lack of freedom and managing the emotional state of the consumer during treatment (Luthi, et al., 2012).

Experience of consumers

Continuing usual life

Home treatment saved time which allowed more time for usual activities (Hall & Lloyd, 2008; Johansson, Bjorkholm, Wredling, Kalin, & Engervall, 2001; Johansson, Langius-Eklof, Engervall, & Wredling, 2005), reduced interruption to their routine (Anderson, et al., 2003; Italiano et al., 2006), allowed consumers to spend more time with friends/family members (Crisp, Koop, King, Duggleby, & Hunter, 2014; Johansson, et al., 2005) and was convenient, especially for those with small children (Hall & Lloyd, 2008). This model also allowed the family to feel involved and consumers remained connected to home life (Johansson, et al., 2001), to live a normal life (Ademokun, Kaznica, & Deas, 2005; Johansson, et al., 2005; Rowe, Valle, Swindell, Fitzsimmons, & James, 2002), freedom (Anderson, et al., 2003; Johansson, et al., 2001; Luthi, et al., 2012) autonomy, (Comerford & Shah, 2018; Johansson, et al., 2001; Luthi, et al., 2012; Rowe, et al., 2002), independence from hospital care (Johansson, et al., 2005), flexibility (Johansson, et al., 2001) and to maintain their identity (Crisp, et al., 2014). OPD treatment facilitated the continuation of work (Comerford & Shah, 2018), treatment in a community clinic closer to home allowed normality (Pace et al., 2009), minimised disruption to life/family and allowed consumers to access their support networks and build rapport with clinicians (Bakker, DesRochers, McChesney, Fitch, & Bennett, 2001).

Impact on consumer resources - travel/waiting/cost

Travel to the main cancer OPD was problematic for consumers (Hall & Lloyd, 2008; Mitchell 2013), it was perceived as a burden for both consumers and their family which increased distress (Bakker, et al., 2001). Treatment in a community clinic closer to home was beneficial as it reduced waiting and travel times (Pace, et al., 2009). Cost was a significant problem with OPD treatment (Hall & Lloyd, 2008; Mitchell 2013), including parking, petrol and caregiver time (Mitchell 2013). Treatment at a local community clinic away from the main cancer hospital was convenient and reduced the cost of car parking (Corrie et al., 2013). Avoidance of travel was perceived as an advantage of home treatment (Anderson, et al., 2003; Italiano, et al., 2006; Lal et al., 2015), which reduced costs for the family (Crisp, et al., 2014). Consumers described waiting at OPD clinics as distressing, tiring and a waste of time (Hall & Lloyd, 2008; Mitchell 2013). A benefit of home treatment was the avoidance of waiting for treatment (Italiano, et al., 2006; Johansson, et al., 2001; Johansson, et al., 2005; Lal, et al., 2015). Treatment in a community clinic closer to home was preferred by consumers due to reduced waiting and travel times, although there were no differences in satisfaction (Pace, et al., 2009).

Psychological impact

Consumers experienced reduced stress/anxiety when undergoing nurse administered treatment at home (Anderson, et al., 2003; Italiano, et al., 2006; Keshvani et al., 2019). Home treatment facilitated coping and adaptation to cancer treatment (Crisp, et al., 2014; Hall & Lloyd, 2008) and fostered a positive attitude (Crisp, et al., 2014). There was reduced anxiety about chemotherapy with home/OPD treatment (Joo, Rha, Ahn, & Kang, 2011), consumers felt relaxed which benefitted the whole family (Pace, et al., 2009). Treatment at home provided comfort (Anderson, et al., 2003; Joo, et al., 2011; Keshvani, et al., 2019; Luthi, et al., 2012) and security (Crisp, et al., 2014; Hall & Lloyd, 2008). Although some consumers (and their caregivers) preferred OPD treatment to keep chemotherapy (representing illness) and home separate (Corrie, et al., 2013), and because it allowed peer support and social connection with other consumers (Corrie, et al., 2013; Hall & Lloyd, 2008). There were higher levels of depression in those receiving treatment in a community GP setting compared with an OPD attached to a hospital but no difference in quality of life (Corrie, et al., 2013). Some consumers undergoing treatment at a community OPD reported concern about the possibility of complications and lack of clinician support (Hall & Lloyd, 2008), but other consumers reported similar anxiety levels with treatment at a main cancer centre versus a community clinic (Pace, et al., 2009).

Safety

Consumers felt safe with nurse delivered home (Keshvani, et al., 2019) and OPD chemotherapy administration (Comerford & Shah, 2018). Some consumers perceived OPD to be safer than home treatment due to the presence of expert staff (Corrie, et al., 2013). Home blood product administration was perceived as safer than hospital-based

treatment by some consumers requiring ongoing blood transfusion whilst most felt they were equivalent (Ademokun, et al., 2005). Consumers who self-administered intravenous treatment were satisfied with the support/level of supervision provided by nurses and doctors and felt safe self-administering at home (Johansson, et al., 2001; Johansson, et al., 2005). Consumers identified that the provision of information, step by step explanation of clinical practice by nurses, knowledgeable clinicians (Alpenberg, Joelsson, & Rosengren, 2015), available hospital support staff (Rowe, et al., 2002), and clear communication between clinical settings/clinicians increased their perception of safety (Bakker, et al., 2001). Weekly appointments at the OPD (oncology day centre) was perceived as an opportunity to be checked by clinicians (Paras-Bravo et al., 2018). At home, consumers identified that they felt reassured with a caregiver present (Luthi, et al., 2012). Consumers felt unsafe if nurses were unsure about clinical practice, didn't adhere to hand hygiene protocols or referred frequently to learning materials whilst performing a clinical procedure (Alpenberg, et al., 2015).

Privacy

Consumers identified that the privacy of home was beneficial (Hall & Lloyd, 2008; Lal, et al., 2015), home treatment ensured confidentiality (Hall & Lloyd, 2008) and allowed symptoms such as vomiting and diarrhoea to be managed privately (Crisp, et al., 2014). The OPD was perceived by some as a small space, frantic and noisy, with little privacy (Comerford & Shah, 2018; Hall & Lloyd, 2008) and it was awkward when side effects occurred in this public space (Comerford & Shah, 2018). Other consumers didn't report issues about privacy in the OPD (Mitchell 2013) and some who had undergone both home and OPD treatment identified there were privacy issues with both settings (family witnessing chemotherapy administration and proximity of other consumers in the OPD) (Corrie, et al., 2013).

Information/adaptation

Most consumers who self-administered treatment were satisfied with the information provided by clinicians and adapted to the skills needed over time, previous experience with OPD chemotherapy helped with adaptation. However, some reported that they received little education (Johansson, et al., 2005). Consumers undergoing nurse provided home treatment, reported that they retained more information at home than in hospital as they found the hospital setting overwhelming (Crisp, et al., 2014). Consumers felt relaxed at home, there were less distractions which aided in understanding information and they also felt comfortable in asking questions (Hall & Lloyd, 2008). Consumers were more satisfied with the explanation of the chemotherapy schedule and side effects when undergoing home compared to hospital treatment (Keshvani, et al., 2019).

Perception of care/clinician competence

Consumer perception of care varied, some had no preference whilst others preferred home treatment as they established trust/rapport with clinicians (Corrie, et al., 2013), which was conducive to the development of the nurse/patient relationship (Hall & Lloyd, 2008). Home treatment with a visiting nurse was personalised (Crisp, et al., 2014; Hall & Lloyd, 2008; Lal, et al., 2015), consumers had the nurses 'undivided attention' (Hall & Lloyd, 2008), and developed a high level of trust due to the time spent with them and the small number of staff visiting (Crisp, et al., 2014). Continuity of care was more apparent with home treatment compared with hospital (Hall & Lloyd, 2008), most were satisfied with the care/communication provided by nursing staff at home (Italiano, et al., 2006) and some thought nursing care was better at home (Anderson, et al., 2003). Others had a negative experience at home due to lack of assistance and limited access to symptom controlling medications (e.g. laxatives) (Keshvani, et al., 2019), or were dissatisfied with the clinical skills/competence of nursing staff (Italiano, et al., 2006). Reliance on one medical specialist was perceived as a disadvantage with home treatment (Lal, et al., 2015). Consumers who managed an element of treatment (disconnected the infusion) at home identified that they were motivated to participate in their own care and reported that they took part in decision making, but some felt the decision was too rapid (Johansson, et al., 2005). However, they felt supported during treatment as they were able to telephone the OPD whenever they required clarification. Consumers identified that clinical competence varied across settings (community clinic versus major cancer centre) (Alpenberg, et al., 2015), consumers changed treatment location to the major cancer centre due to perception of increased clinical expertise (Alpenberg, et al., 2015; Bakker, et al., 2001). Other consumers reported that they trained less experienced nurses in the community clinic setting (Alpenberg, et al., 2015). Whilst some consumers preferred the community clinic over the main cancer centre as there was less disruption to their life even though clinicians were perceived to have less clinical expertise. However, they were only willing to undergo treatment at the community clinic if clinicians from different settings were communicating effectively (Bakker, et al., 2001).

Consumers with infection

Experience of caregivers

Community-based intravenous treatment was beneficial for caregivers due to reduced burden associated with travelling to hospital. Caregivers of consumers who lived in residential aged care facilities thought treatment at the facility was safer and higher quality compared to hospital-based treatment (Papaioannou et al., 2018). Consumers receiving treatment benefited from the existing relationship between clinical staff and consumers. Allowing consumers to remain in the aged care facility, a familiar environment for them, meant lower risks of fall and pressure injuries

(Papaioannou, et al., 2018). For consumers who were discharged home to have intravenous treatment, caregivers expressed a desire to be included in the information/medical sessions and part of the decision-making in initiating intravenous treatment at home (Berrevoets et al., 2018).

Experience of consumers

Adaptation and continuing life

The shift of intravenous treatment to the home required significant adaptation by consumers, especially when antibiotics were self-administered (Keller, Cosgrove, et al., 2019a; Keller, Cosgrove, et al., 2019b). Consumers used strategies like visual aids and phone alerts to aid administration of the infusion (Keller et al., 2020). Although many consumers eventually adapted to self-administration (Keller, Cosgrove, et al., 2019a; Keller, Cosgrove, et al., 2019b; Twiddy et al., 2018), the process of adaptation was not without challenges. The workload in self-administering was significant. Some consumers shared the responsibility with caregivers (Keller, Cosgrove, et al., 2019a) and others learnt to multitask infusion with other activities (e.g. commuting) (Keller, Cosgrove, et al., 2019b; Twiddy, et al., 2018). Physical (i.e. recovering from infection) and cognitive factors were a barrier for completing administration tasks (Keller, Cosgrove, et al., 2019a; Twiddy, et al., 2018). Consumers dedicated significant time and effort to self-administer at home without the presence of a clinician, which limited the possibility of engaging in other activities (Twiddy, et al., 2018). Nurse administered treatment at home or OPD allowed many consumers to continue employment, and home treatment reduced travelling which minimised costs and time (Stephens, 2013; Tonna et al., 2019).

Impact on self

Home-based intravenous treatment promoted autonomy and privacy (Berrevoets, et al., 2018; Kieran, O'Reilly, Parker, Clarke, & Bergin, 2009; Saillen et al., 2017). It allowed consumers to feel 'normal' (Stephens, 2013) and allocate time to care duties, paid employment and treatment (Kieran, et al., 2009) and it enhanced their well-being (Stephens, 2013). Waiting for the clinician to visit decreased autonomy and privacy, consumers preferred more flexible home visits or wanted to have input into nursing visit scheduling (Berrevoets, et al., 2018). The lack of clinical supervision was a disadvantage for those having treatment at home (Kumari, Ritchie, Thomas, & Jull, 2018) which heightened anxiety over adverse events. This anxiety led some to refuse to self-administer treatment (Tonna, et al., 2019). Some consumers preferred OPD based intravenous treatment as it offered opportunities for socialising with other consumers (Tonna, et al., 2019).

Experience and perception of care

The decision to initiate community-based intravenous treatment was often made without consulting consumers (Berrevoets, et al., 2018; Kieran, et al., 2009; Tonna, et al., 2019). The experience of transition to home-based intravenous treatment was shaped by the presence of a clinician who was responsible for their care. The experience was positive when such a clinician could be identified, and poor when there was confusion about who was responsible for care (Berrevoets, et al., 2018). Consumers were confident when clinicians were skilled and competent (Berrevoets, et al., 2018; Saillen, et al., 2017; Stephens, 2013; Twiddy, et al., 2018), their queries were addressed (Kumari, et al., 2018; Saillen, et al., 2017) and they appreciated the emotional support provided by clinicians (Stephens, 2013). However, lapses in infection control in home-based care raised concerns (Stephens, 2013). Consumers receiving treatment in a residential care facility did perceive that care was high-quality, intravenous antibiotic infusions were missed and there was a delay in responding to vascular access device complications (Mansour, Arbaje, & Townsend, 2019).

Consumers attending OPD for treatment found it challenging due to time and travel requirements and delays (Kumari, et al., 2018; Twiddy, et al., 2018). For those with multiple morbidities, travelling to the OPD was more of a burden than hospital admission (Twiddy, et al., 2018). There was uncertainty about delivery times of supplies for those self-administering at home (Keller, et al., 2020; Stephens, 2013; Twiddy, et al., 2018) and consumers were also uncertain about follow-up required when treatment had finished (Twiddy, et al., 2018).

Information/learning/knowledge

Some consumers felt confident about self-administration given training was provided (Tonna, et al., 2019). Consumers with experiences in self-administration viewed formal training as essential (Keller, Cosgrove, et al., 2019a; Twiddy, et al., 2018) it prepared them to be a "lay health care worker" (Keller, Cosgrove, et al., 2019a). To become competent in self-administration, consumers brought friends who were clinicians to translate medical jargon, took notes and transferred prior training experience to assist learning (Keller, Cosgrove, et al., 2019a). Most consumers felt that information and training provided for self-administration was adequate (Kieran, et al., 2009; Kumari, et al., 2018), but some viewed the materials provided as low quality (Kumari, et al., 2018; Saillen, et al., 2017). Information provision remained equally important when treatment was nurse-administered, however, the quality of information provision was mixed, it was described as inconsistent (Berrevoets, et al., 2018; Kumari, et al., 2018) and insufficient (Saillen, et al., 2017; Stephens, 2013). Often only verbal information was provided (Berrevoets, et al., 2018). Consumers were frustrated by this (Stephens, 2013) and caregivers searched the internet for information accordingly (Berrevoets, et al., 2018).

Safety.

Consumers felt safe when clinicians provided care in a hygienic manner (Berrevoets, et al., 2018). Reduced hospital-acquired infection was cited to be a benefit of home-based intravenous treatment (Stephens, 2013; Twiddy, et al., 2018). Knowing they had access to clinical expertise, whether on site (Berrevoets, et al., 2018; Twiddy, et al., 2018) or remotely

(Keller, Cosgrove, et al., 2019a) offered a sense of security. In addition, consumers valued reminders/booklets with information about intravenous administration (Twiddy, et al., 2018) When information was lacking, a sense of insecurity ensued (Berrevoets, et al., 2018).

Table 5. Consumer experience of central vascular access devices (CVADs) and auxiliary products

Consumers with cancer

Discomfort

Most consumers found that the central venous access device (CVAD) insertion site and dressing were comfortable, but some consumers reported pain, especially at the insertion site (Park & Lee, 2020). There was discomfort associated with insertion, removal, CVAD complications and with cannulation if the device malfunctioned (Ritchie, Kelly, Moss, Paul, & Shaw, 2015). For some consumers with a totally implanted venous access device (TIVAD), discomfort at the insertion site affected sleep. Discomfort was exacerbated by certain movements, seat belts and their 'bra' strap (Goossens, Vrebos, Stas, De Wever, & Frederickx, 2005). Some consumers thought that the pain associated with needling a TIVAD was much worse than venepuncture (Minichsdorfer et al., 2016). Other consumers were positive about the TIVAD as it reduced discomfort during chemotherapy administration and allowed them to avoid peripheral venepuncture (Goossens, et al., 2005). Whilst many consumers with a peripherally inserted central catheter (PICC) found the insertion site/dressing comfortable (Källenius Edström, Lindqvist, & Rosengren, 2016), some found the PICC insertion site ached and the dressing was uncomfortable, mainly due to sweating under the dressing and securement device (Alpenberg, et al., 2015; Källenius Edström, et al., 2016).

Resources

For some consumers that were required to pay for CVAD care, the high costs associated with PICC care (dressing supplies and nursing care) had an impact on the whole family, which led to worry and guilt for the consumer (Ai et al., 2021). Some consumers delayed dressing changes due to the burden of travel to the OPD, long waiting times in the OPD and to avoid travel due to chemotherapy side-effects such as fatigue (Ai, et al., 2021).

Reducing venepuncture

A benefit of a CVAD was the reduction in venepuncture (peripheral cannulation and phlebotomy) (Alpenberg, et al., 2015; Chernecky, 2001; Kelly & Snowden, 2021; Paras-Bravo, et al., 2018; Rowe, et al., 2002). Consumers with a TIVAD described the benefit of decreased pain and bruising from fewer venepuncture attempts (Chernecky, 2001), those who were able to have blood samples taken from the TIVAD reported a significant reduction in therapy burden (Minichsdorfer, et al., 2016). Consumers preferred a PICC over the repeated use of peripheral veins (phlebotomy /peripheral cannula insertion) as they had damaged veins and required multiple attempts (Källenius Edström, et al., 2016) and it made treatment more convenient (Ai, et al., 2021).

Responsibility

Consumers with a tunnelled catheter identified that they felt they had a responsibility for CVAD care (self-care and RN care) (Moller & Adamsen, 2010). For those with a PICC, some consumers were uneasy about the expected level of involvement in terms of the PICC and felt the assumption that they or their caregivers would monitor for adverse events was too much responsibility (Molloy, Smith, & Aitchison, 2008).

Psychological impact

Consumers reported that they wanted control over their treatment, including CVAD choice (Ritchie, et al., 2015). Many consumers were accepting and positive about the CVAD (Park & Lee, 2020), even those that experienced an adverse event (Ryan et al., 2019). For others, the CVAD was viewed as a 'necessary evil' (Ritchie, et al., 2015) or a 'necessary tool' which enabled recovery but was also a threat to their health (Moller & Adamsen, 2010). Consumers were protective of the CVAD for self-preservation (Ritchie, et al., 2015). Some CVADs (e.g. tunnelled catheters) were perceived as more invasive than others and consumers thought that this made them look more ill than they felt (Ritchie, et al., 2015). The attitude of those with a tunnelled catheter toward their CVAD varied from acceptance to revulsion (Moller & Adamsen, 2010).

For consumers with a PICC, the CVAD was perceived as a tool to enable recovery from illness and extend their life (Alpenberg, et al., 2015) and most would recommend a PICC to others (Molloy, et al., 2008). Some consumers viewed the device as a symbol of disease and looked forward to PICC removal as it signified treatment completion (Alpenberg, et al., 2015). Consumers with a PICC or tunnelled catheter identified that the CVAD impacted physical relationships due to a fear of dislodgement and discomfort about the perceptions of others (Moller & Adamsen, 2010; Ryan, et al., 2019), concern about the perception of others led to one consumer avoiding leaving the house which meant that they didn't attend the OPD for PICC dressings (Ai, et al., 2021). Some were uncomfortable interacting with their children due to presence of the PICC (Paras-Bravo, et al., 2018). Some consumers felt ambivalent (Molloy, et al., 2008) or distressed about the PICC, especially when people asked about the device (Oakley, Wright, & Ream, 2000).

Although the PICC allowed independence and made treatment easier (Molloy, et al., 2008), a disadvantage with these CVADs was the regular care required and resulting dependency on the health care system (Moller & Adamsen, 2010; Ritchie, et al., 2015). Some consumers were trained to self-manage their CVAD which gave them independence which they valued (Moller & Adamsen, 2010).

Consumers with a TIVAD disliked the psychological effect of a foreign device in their body (Chernecky, 2001), however, the TIVAD was convenient (Goossens, et al., 2005), low maintenance (Chernecky, 2001), allowed freedom as there were no external parts (when the TIVAD was de-needed) (Ritchie, et al., 2015) and most consumers felt secure with a TIVAD, which allowed them to feel comfortable enough to socialise (Kreis et al., 2007). Some consumers were impressed with the mechanics of their device and described showing it to others with a sense of awe, they perceived that their device was superior to a PICC/tunnelled catheter (Ryan, et al., 2019). Although some consumers found that the positives of a TIVAD were limited by adverse events, pain, the insertion site wound (Ritchie, et al., 2015) and ongoing maintenance required after treatment ceased (Kreis, et al., 2007).

The TIVAD reduced distress associated with chemotherapy treatment for some consumers (Chernecky, 2001) and most reported that they would chose a TIVAD for chemotherapy administration again, including those who had their TIVAD removed and reimplanted due to an adverse event (Minichsdorfer, et al., 2016). The TIVAD allowed quicker access for emergency treatment and blood sampling (Chernecky, 2001), facilitated treatment (Minichsdorfer, et al., 2016) and accelerated processes in the hospital (Kreis, et al., 2007).

Hiding the CVAD

Consumers described stigma, a need to conceal or hide the CVAD (Ritchie, et al., 2015). Some consumers with a TIVAD found the device was more discreet than other CVADs (Ritchie, et al., 2015), whilst other consumers felt that the visibility of the TIVAD was a disadvantage (Goossens, et al., 2005).

Some consumers with a PICC or a tunnelled catheter adapted their clothing to hide their CVAD (Ritchie, et al., 2015), and the aesthetics of a PICC was identified by others as a disadvantage and consumers used a dressing/bandage to hide the device (Paras-Bravo, et al., 2018). The ability for people to see the pump/tubing was emotionally difficult for some consumers with a tunnelled catheter or TIVAD, they avoided public places as they didn't want people to think they were unwell (Johansson, et al., 2005).

Some consumers reported that relatives expressed disgust and fear when they saw the PICC and they made sure they covered it to prevent this (Alpenberg, et al., 2015), other consumers felt it was best to avoid crowds (Molloy, et al., 2008). The hospital supplied arm cover was described as ugly and unseemly and some consumers made their own cover from clothing to hide the PICC (Alpenberg, et al., 2015).

Adaptation

Living with a CVAD presented distinct challenges, usual activities required adjustments and adaptations, which led to uncertainty for some consumers (Ryan, et al., 2019). The CVAD complicated ordinary activities, some consumers were hesitant about participating in social activities or performing hygiene activities such as a bathing (Park & Lee, 2020). Continuity of daily life was a priority for consumers (Ritchie, et al., 2015; Ryan, et al., 2019), and they were motivated to develop strategies to promote adaptation and minimise disruption to their life (Ritchie, et al., 2015). When consumers found it difficult following clinical recommendations, some disregarded the advice provided by health care professionals (Ryan, et al., 2019).

Consumers with a PICC or tunnelled catheter were reminded of the device frequently, especially when bathing and dressing (Ryan, et al., 2019), there were practical challenges in keeping the catheter dry, clean and secure which was exacerbated when an elastomeric pump was attached (Ryan, et al., 2019).

For consumers with a TIVAD, the freedom to use their arms during activities of daily living (Goossens, et al., 2005) and chemotherapy (Chernecky, 2001) was beneficial. However, the TIVAD impaired usual activities - exercise, walking, sleeping, carrying/lifting and showering (Minichsdorfer, et al., 2016) and for some, the site was uncomfortable which affected their sleep (Chernecky, 2001). Other consumers found that the TIVAD had minimal impact on usual activities, with some able to continue work (Kreis, et al., 2007). Some consumers reported that the elastomeric pump hindered usual activities rather than the TIVAD, although they were still cautious with the unattached TIVAD initially, especially when sleeping (Ryan, et al., 2019). Consumers with experience with other CVADs reported that a TIVAD was more discreet, secure and had less impact on usual activities (Ryan, et al., 2019).

The PICC made usual activities including washing, dressing and sleeping more difficult (Alpenberg, et al., 2015; Molloy, et al., 2008). Adaptation was required for consumers with a PICC, with modifications to sleeping, bathing and clothing choice (Oakley, et al., 2000; Paras-Bravo, et al., 2018) and some found the adaptation difficult (Molloy, et al., 2008). Usual activities (leisure, work, household duties, childcare) were considered a threat to the PICC (Paras-Bravo, et al., 2018). The ability of consumers to continue working with a PICC depended on job type and risk, those in 'dirty' manual labour positions were required to stop working (Oakley, et al., 2000). Some consumers found showering more difficult with an electronic pump attached to the PICC (Keshvani, et al., 2019). The device restricted usual hygiene and exercise routines and some found the PICC restricted arm movements (Källenius Edström, et al., 2016). The weekly PICC dressing appointment also restricted their life (Källenius Edström, et al., 2016). Younger consumers reported greater restrictions on usual activities because of the PICC (Paras-Bravo, et al., 2018). However, most consumers adapted

to the PICC over time and continued usual daily activities (Källenius Edström, et al., 2016; Molloy, et al., 2008; Paras-Bravo, et al., 2018). Some consumers described the need for adaptation as insignificant compared to the importance of treatment (Oakley, et al., 2000). The tubing connecting the elastomeric pump to the vascular access device also hindered usual activities for those with a tunneled CVC or TIVAD (Johansson, et al., 2005). However, many consumers carried on with usual life, eating at restaurants, catching public transport and paid employment. For those who continued work, most reported that this was positive, but their role required some modifications to reduce risk to their CVAD (Johansson, et al., 2005).

Adverse events

Consumers with a CVAD reported anxiety and uncertainty about adverse events, especially occlusion (Park & Lee, 2020). Consumers with a TIVAD undergoing nurse provided treatment at home were concerned about side effects and the impact that this may have on caregivers (Luthi, et al., 2012), the main dissatisfaction with a TIVAD was the 'fear of complications' (Kreis, et al., 2007). Consumers were also concerned that the pump may dysfunction (Luthi, et al., 2012). Those with a tunneled CVC or TIVAD who self-administered treatment at home described worry about handling the vascular access device and potential complications, but this dissipated over time as they gained more experience with the procedure (Johansson, et al., 2005). Concern about potential adverse events for consumers with a PICC continued even after they had successfully adapted to living with the device (Molloy, et al., 2008). Many were concerned about infections (Ai, et al., 2021; Källenius Edström, et al., 2016), there was 'anxiety' about bacteria (Alpenberg, et al., 2015) and this fear of infection increased their adherence to scheduled dressing changes (Ai, et al., 2021). However, others weren't adherent with appointments for dressing changes as they didn't think a delay in changing the PICC dressing would impact infection risk (Ai, et al., 2021). Some reported worry about the functioning of the PICC, they were uncertain about the longevity of the PICC and whether it would require replacement (Alpenberg, et al., 2015; Källenius Edström, et al., 2016), they worried that they would damage the PICC whilst sleeping, playing with children and hugging loved ones (Källenius Edström, et al., 2016). Consumers were also concerned that their friends and families also worried about the PICC (Molloy, et al., 2008). However, many had a positive experience with timely responses by clinicians to issues related to equipment (pump and CVAD) (Keshvani, et al., 2019).

Knowledge/understanding

Many consumers were satisfied with information provided about the CVAD (Park & Lee, 2020). Whilst most consumers who were self-administering treatment at home with a TIVAD or CVC understood how the CVAD and the elastomeric pump worked (Johansson, et al., 2001), some felt that they did not receive enough information about the CVAD (Johansson, et al., 2005). Consumers with a PICC, TIVAD or tunneled catheter felt underprepared for living with a CVAD and some explicitly called for improved information provision for consumers in the future (Ryan, et al., 2019). Some consumers with a PICC reported that they received enough information, but they found retaining information and problem solving independently difficult at home (Oakley, et al., 2000). Most consumers with a TIVAD wanted information and many wanted this information prior to TIVAD implantation whilst others wanted information after insertion but prior to use (Piredda, Migliozzi, Biagioli, Carassiti, & De Marinis, 2016). Most consumers wanted to receive information about the TIVAD from the oncologist or CVAD inserter, others from the Oncology RN (Piredda, et al., 2016). Some consumers with a TIVAD reported they received little to no information about the TIVAD (Piredda, et al., 2016) and others demonstrated a unique knowledge gap; many were unclear as to how long their device would remain in place and what this might mean for ongoing care and support (Ryan, et al., 2019).

Those with a tunneled catheter found that their understanding of care of their CVAD was based on observing the practice of clinicians providing care (Moller & Adamsen, 2010). Those self-administering treatment with a tunneled catheter gained confidence by handling infusers prior to discharge (inpatients with elastomeric device for initial 24 hours) (Rowe, et al., 2002). Increased knowledge about CVAD care presented problems for some consumers when clinicians cared for their CVAD incorrectly which led to conflict (Moller & Adamsen, 2010). Consumers advocated for themselves if they perceived that the nurse had poor clinical skills (Ritchie, et al., 2015).

Satisfaction with information for consumers with a PICC varied, some were satisfied with the information provided prior to insertion, they understood how their PICC worked and why they had a PICC inserted (Källenius Edström, et al., 2016; Molloy, et al., 2008). However, some were only partially satisfied with information (Källenius Edström, et al., 2016), disadvantages were not discussed prior to insertion e.g. requirement to have a bandage on the arm for months (Källenius Edström, et al., 2016). Some consumers struggled with information, it was unhelpful, they felt overwhelmed with the amount of information and some found it to be frightening and difficult to remember (Molloy, et al., 2008). Some lacked health knowledge, they didn't know they were required to check the PICC or why dressing changes were required (Ai, et al., 2021). Information preference varied, with most wanting as much information as possible, others thought too much information was a negative (Molloy, et al., 2008).

Perception of care

Many consumers found that clinician supports for the CVAD outside the hospital were sufficient (Molloy, et al., 2008; Park & Lee, 2020), their confidence increased with support from community-based nurses, family support and through the 24-hour support offered by the Oncology department (Oakley, et al., 2000). For those with a PICC, the careful handling of the PICC by nurses increased the consumer perception of safety (Alpenberg, et al., 2015). Some consumers were dissatisfied with clinical care of the TIVAD outside hospital (Joo, et al., 2011;

Kreis, et al., 2007), consumers perceived that clinical competence varied across settings, those with a tunneled catheter, perceived that some nurses lacked knowledge and were resistant to listening to them and collaborating in CVAD care (Moller & Adamsen, 2010). Some with a PICC distrusted local hospitals due to the lack of PICC specialists, which was thought to increase the risk of infection, dislodgement and catheter rupture and others reported that they suffered skin allergies from the dressing used by the local hospital (Ai, et al., 2021). For some, this meant that they avoided the local hospital for dressing changes, instead they asked family members (both clinicians and non-clinicians) to change the dressing (Ai, et al., 2021). This lack of experience/knowledge about CVAD management outside of specialist settings led to delay, inconvenience and worry which was heightened for those with a TIVAD (Ryan, et al., 2019). Consumers with a PICC or TIVAD were dissatisfied that some clinical sites wouldn't use the CVAD to take blood samples (Alpenberg, et al., 2015; Chernecky, 2001).

Consumers with infection

Adaptation

Daily life was impacted by the presence of the infusion set when intravenous treatment was completed at home (Kumari, et al., 2018). Consumers found it difficult to keep the dressing dry and were required to modify hygiene activities to keep the dressing intact (Berrevoets, et al., 2018; Keller, et al., 2020; Kumari, et al., 2018). Consumers used plastic wrap during a shower and often asked friends/families to help wrap their arm whilst others avoided showering and washed themselves at the sink (Keller, Cosgrove, Kohut, et al., 2019). A few consumers simply stopped washing or showering to reduce harm to the CVAD (Keller, Cosgrove, Kohut, et al., 2019). Most consumers/caregivers identified keeping the CVAD dressing dry whilst showering/bathing was the most significant barrier to safe treatment at home (Keller, et al., 2020). Cooking and cleaning were perceived as a hazard, some stopped these activities, others covered their CVAD with extra clothing to reduce risk (Keller, Cosgrove, Kohut, et al., 2019).

The infusion set limited consumers' mobility (Berrevoets, et al., 2018; Kumari, et al., 2018). To prevent device dislodgement, consumers had to pay extra care to household clutter and pets when moving around (Keller, Cosgrove, Kohut, et al., 2019; Keller, et al., 2020). In addition, those with a pet worried that pet hair/waste might increase the risk of infection and in the absence of clear clinical recommendations on pets, some consumers asked others to take over care of their pet to be safe (Keller, Cosgrove, Kohut, et al., 2019). Self-administration of antibiotics at home required consumers to take on more advanced care roles and responsibilities including scheduling their infusions in relation to phlebotomy requirements, troubleshooting issues with the CVAD and monitoring when the CVAD dressings were required to be changed (Keller, Cosgrove, et al., 2019a). CVAD complications made treatment more complicated than they expected (Saillen, et al., 2017) and consumers solved some of these issues independently or by accessing clinical support (Keller, et al., 2020).

Psychological impact

Some consumers with a PICC were required to adapt in social situations as the visibility of this CVAD created fear of being judged (Twiddy, et al., 2018). Some consumers felt that clinicians did not acknowledge the distress/fear they had about living with a CVAD (Twiddy, et al., 2018).

Information, understanding and knowledge

Some consumers felt unprepared to go home and care for the CVAD/pump (Keller, Cosgrove, et al., 2019a). Consumers desired two types of information: how to manage the CVAD/auxiliary equipment and how to live with a CVAD (Berrevoets, et al., 2018; Keller, et al., 2020). Some consumers were satisfied about the education provided about the CVAD (Berrevoets, et al., 2018; Saillen, et al., 2017), others did not understand the information, including the purpose and risks associated with the CVAD and pump instructions (Keller, et al., 2020). Some received contradictory information regarding the action required when infusate was left in the elastomeric device after the infusion had ceased (Berrevoets, et al., 2018). Consumers also voiced a lack of information on how to live with a CVAD including showering and other daily activities (Keller, et al., 2020; Twiddy, et al., 2018) and what a day like looked like to live with a PICC (Berrevoets, et al., 2018). The delivery of information was described as rushed, inconsistent and difficult to understand due to medical jargon (Berrevoets, et al., 2018; Keller, et al., 2020).

Consumers' perception of clinicians' knowledge

As consumers gained increasing experience and knowledge about the CVAD, some found that nurses lacked knowledge and clinical practice was inconsistent e.g. PICC dressing changes (Kumari, et al., 2018).

Experiences and attitudes toward adverse events

Many consumers expressed fear of an adverse event with their PICC or other CVAD (Mansour, et al., 2019; Saillen, et al., 2017; Twiddy, et al., 2018). Consumers were also concerned about complications with auxiliary equipment such as pump failure (Kumari, et al., 2018; Saillen, et al., 2017).

Consumers with infection or cancer

Understanding information

Consumers were satisfied with the training provided about using a 'smart' pump for self-administration of treatment at home (Brown, Michael, & Grady, 2018). Whilst consumers with a PICC described the information given by medical staff as minimal, technical, and difficult to understand (Sharp et al., 2014).

Adaptation

Consumers with a 'smart' pump reported difficulties with pump alarms, changing the infusion set and priming the intravenous line (Brown, et al., 2018). However, they were able to resolve most pump alarms using information displayed on the pump screen without contacting clinical staff. Whilst those with an elastomeric pump found it restricted mobility, and the line was a hazard for dislodgement which required vigilance to prevent catching on household objects (Sharp, et al., 2014). The PICC also required changes to daily activities to protect the PICC, showering with a PICC was challenging, but consumers adapted over time (Sharp, et al., 2014).

Attitude toward the CVAD

For many consumers, the PICC began to symbolise their disease and treatment progress and some consumers were frightened by the tip location of the PICC near their heart. Many consumers held a positive attitude towards the PICC, it aided treatment and allowed freedom to be discharged home to receive treatment and freedom from repeated venepuncture (Sharp, et al., 2014).

Adverse Events

Consumers experienced concerns and worries over PICC complications initially but became more confident over time and their anxiety reduced. Many consumers who suffered an adverse event (deep vein thrombosis or infection) remained positive about the PICC as it allowed them to avoid multiple venepunctures and viewed these complications as inconvenient rather than a life-threatening event (Sharp, et al., 2014).